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Parental Wellbeing: Stress, Parental Sense of Competence, Social Support and Hope in parents of children with and without Autism Spectrum Disorder

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Declaration

The work that has been produced is original and has not been submitted in relation to any other degree or qualification.

Signed:

Date:

Acknowledgement

My sincerest thanks are expressed to my supervisor, Dr Linda O'Neill for her expert knowledge and guidance throughout this study.

Meeting log

University of Chester

Department of Psychology

Research Module Meeting Log 2017/2018

NAME: Kerry Keane

SUPERVISOR: Dr Linda O'Neill

Date	Discussion topics
08/11/17	Discussed possible topics for investigation into an independent project.
22/11/17	Decided on the area of investigation for an independent project. Agreed that this would be looking at the well-being of parents raising a child with disabilities/autism. Discussed plans to submit project proposal.
17/01/18	Ethics form sections and clarified the areas that were less explanatory. Also discussed writing up an information and a debrief sheet for participants who would take part in the investigation.
31/01/18	Changes to be made on ethics form, such as linking appendices consistently throughout. Also went through the Bristol Online Survey systems, as a refresher on how to use it.
28/02/18	After ethics had been approved, participant recruited should start ASAP. Also debated requirements for study, e.g. number of participants that would be needed for optimal testing and about the recent literature in the area relevant to the literature review.
14/03/18	Ideas for research to include in the literature review and how to best present each section. Also discussed how to recruit more participants.

09/05/18	Timing of when to close online survey and how to recruit more participants before this was done. Also discussed how to reverse score scales for analyses, and how to separate the sub-scales to test.
20/06/18	Analysis for investigation, how to transfer data from BOS to SPSS and the normality/homogeneity results of sample. From this, we decided on the tests that would be used in analysis. Also discussed that data cells with large amount of information missing would be removed so not to have a large impact on results.
28/08/18	Spoke about draft feedback, specifically regarding presentation of results and tables that were included in the results section.
20/09/18	Final discussion about analysis, how to format dissertation and meeting log.

SIGNED
STUDENT _____ DATE: 20/9/18

SUPERVISOR _____ DATE: 20/9/18

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Abstract

Parents of children raising a child with a disability, including Autism Spectrum Disorder (ASD), often report higher levels of stress than parents of typically developing (TD) children. Much research focuses on the psychological impact of caring for a child with additional needs, with little providing a more inclusive insight into the overall effect on parental functioning. The current study used multiple self-report measures to explore stress, parental sense of competence, social support and hope in parents raising a TD child compared to those raising a child with a disability or ASD. Results showed significant differences between the groups. Parents raising a child with ASD reported the highest level of stress, and alongside parents raising a child with a disability, had significantly higher levels than parents raising a TD child. Additionally, parents of children with a disability and ASD had significantly lower perceived parental competence, social support and hope than parents of TD children. Further variations between the groups were discussed. The results highlighted that raising a child with a disability or ASD is a unique and variable experience, shaped by a body of factors that need to be reviewed comprehensively to support positive parental adjustment. Implications and suggestions for future research were also discussed.

Parental Wellbeing: Stress, Parental Sense of Competence, Social Support and Hope in parents of children with and without Autism Spectrum Disorder.

As defined in the Equality Act (2010), “a person has a disability if they have a physical or mental impairment and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities”. Parents of persons with a disability, historically and across continents, are notably the most consistent fundamental component in the support, education and development of their children (World Health Organisation, 2012). Since the late 1980’s research has recognised this, creating a shift from understanding disabled children as individuals to an increasing interest on the family as a whole (Kandel & Merrick, 2007; Shelton, Jeppson & Johnson, 1987; Shivers & Kozimor, 2017; Yui et al., 2016). Hence researchers and practitioners need to continually identify the needs and requirements of the family to facilitate engagement and trust and secure the provision of effective support (Kendall, Rodger & Palmer, 2010; Orsmond & Seltzer, 2007; Smith, Cheater & Bekker, 2013). After all, following the typical challenges that occur whilst raising a child, having a child with developmental problems can produce additional difficulties for the parents who take care of them (Feizi, Najmi, Salesi, Chorami & Hoyeidafar, 2014). The literature is abundant with information on the impact of caring for and raising a child with a disability (Bourke-Taylor, Pallant, Law & Howie, 2013; Cadwgan & Goodwin, 2018; Estes et al., 2013; Feizi et al., 2014; Green, 2007; Hartley & Shultz, 2015; Ilias, Cornish, Kummar, Park & Golden, 2018; Pelchat & Lefebvre, 2003). Thus, the purpose of this study was to explore a range of these issues and in doing so, gain a more comprehensive understanding of the relationship

between stress, parental sense of competence, social support and hope, in parents raising children with a disability, including Autism Spectrum Disorder (ASD).

Stress Levels in Parents raising a child with disabilities

Yamaoka et al (2015) conducted a large-scale Japanese study based on pre-existing data and found significant associations between raising a child with a disability and maternal psychological distress. Psychological distress was rated higher for mothers who were primary caregivers as they reported greater activity restriction, low social support and regular hospital visits. However, it should be noted that Yamaoka et al. (2015) had limited information on maternal characteristics or child diagnosis; factors that can influence the mental well-being of parents (Feizi et al., 2014; Hartley & Shultz, 2015). For instance, Japanese culture tends to lead mothers to prioritise family over work, with their parenting style having previously focused on proactively predicting the needs of their child (Kuczynski, 2003); a challenging skill when a child has one or multiple disabilities (Gascoigne, 2014). If this was also the case for the mothers of Yamaoka et al's (2015) research, it may provide some explanation as to why they had a high score of psychological distress, as their need to 'solve' behaviour problems could have created additional pressures (Olin et al., 2010). The limited information on maternal characteristics from the pre-existing data did not allow for further clarification, hence some may argue its reliability, as it did not select information that was fully suited to their objectives (Colepicolo, 2015). However, recently Ilias et al (2018), reviewed 28 papers investigating parents raising a child with ASD in non-Western cultures and concluded that there are important cultural differences between countries that can impact the well-being of mothers raising a child with

ASD, supporting Yamaoka et al's (2015) research and outlining a need for research across cultures for a complete understanding of this issue.

Furthermore, Padden and James (2017) used specific psychometric measures and physiological assessments to examine anxiety and depression levels and compare stress and anxiety between parents with typically developing (TD) children and parents of children diagnosed with ASD. As a stress reaction is characteristic to every person (Oken, Chamine & Wakeland, 2015), studying both physiological and psychological constructs that may play a role in the evolution of stress provides a more in-depth and reliable picture of comparison between the two groups (Lazarus, 1999; Oken et al., 2015; Padden & James, 2017). In line with the literature in this area (Feizi et al., 2014; Hartley & Shultz, 2015; Yamaoka et al., 2015), Padden and James (2017) concluded that parents of children diagnosed with ASD rated themselves higher in stress and anxiety than did parents of TD children. Therefore, substantiating the claim that caring for a child with disabilities can negatively impact parental wellbeing.

However, Padden and James (2017) issue that caution should be taken interpreting self-reported stress from parents, arguing issues of potential bias in studies such as Yamaoka et al's (2015). This is because Padden and James' (2017) physiological assessments found that parents of children with ASD and parents of TD children both fell within the normotensive range of physiological measures, opposite findings compared to their psychometric measurements. Whilst this is acknowledged, changes in physiological features due to stress is not reflected the same across all individuals (Alberdi, Aztiria & Basarab, 2016; Mariotti, 2015) and the psychological effects of stress can persist far longer than its acute effect on physiology (Plarre et al., 2011). Thus, relying on physiological

symptoms as a single measure of parental stress may not accurately represent stress and anxiety levels, as adaptive physiological processes only occur for the body to regain homeostasis and return to normal once this has happened (Stults-Kolehmainen & Sinha, 2014). Though, this could indicate that there are mediating variables influencing both the long and short-term effect of stress in parents who have children with disabilities, warranting further investigation to allow for further insight into the matter.

Parental Sense of Competence

It has been argued that parental sense of competence (PSOC) can impact stress levels in parents raising a child with a disability and ASD (Angley, Divney, Magriples & Kershaw, 2015; Craig et al., 2016; Katkic, Morovic & Kovacic, 2017; Mash & Johnston, 1983; Ozturk, Riccadonna & Venuti, 2014). PSOC is defined by the perceived self-efficacy and satisfaction of parents; how they regard their ability to adjust and adapt to their parenting role to positively influence the development of their child (Belsky, Robins & Gamble, 1984; Katkic et al., 2017; Vukusic, 2018). Accordingly, Mash and Johnston (1983) stated that parents who have a child with a developmental disability (DD) report higher stress which could negatively impact their parental competence. This relates to Padden and James' (2017) research, as PSOC may be an influencing variable in the relationship between stress and parents raising a child with a disability.

Ozturk et al (2014) studied 90 parents of children with ASD using self-report measures. They looked at self-perceptions of the parenting role, to investigate how this related to parental stress. Higher levels of depression and psychological problems were reported by mothers when they perceived lower satisfaction

adapting to their caregiving role, yet fathers expressed lower levels of depression and psychological symptoms the more they thought that they interacted with their child in a structured and mannerly way. Though, overall, they found that mothers reported higher levels of depression and stress than fathers. This is not unusual considering that historically and cross-culturally mothers are considered as primary caregivers, which requires them to possess the physical and psychological resources to support the development of their child (Howard, Martin, Berlin & Brooks-Gunn, 2011; Oliveira, 2018; Raley, Bianchi & Wang, 2012). Even for mothers raising a typically developing child, this societal expectation for women to take more managerial responsibilities in the parental role can cause uncertainty in their parenting abilities (Leskosek, 2011; Mintz, 2015; Scharp & Thomas, 2017). Hence, this may provide some explanation for Ozturk et al's (2014) findings, as a limitation of their research was not including a comparison group (parents with typically developing children). Therefore, it was not possible to compare whether the stress and lower perceived parental competence reported by mothers was due to raising a child with ASD or because gendered expectations elicited feelings of increased managerial responsibilities.

On the other hand, Katkic et al (2017) found that mothers raising children with a DD reported lower levels of stress than mothers with TD children, and that mothers who reported lower stress levels tended to report higher levels of PSOC. They studied 33 mothers raising children with a DD and 38 mothers raising TD children using self-report measures. Their data revealed higher self-perceived parenting efficacy from mothers who had children with a DD than mothers with TD children. Interestingly, this contrasts with a lot of the literature discussing PSOC in mothers of children with a DD (Bourke-Taylor et al., 2013; Craig et al., 2016; Estes

et al., Feizi et al., 2014; Ozturk et al., 2014). However, Katkic et al (2017) failed to describe their inclusion criterion for what they the defined as a DD within their study. As the term DD is used to describe a broad range of issues (Robinson & Neece, 2014; Scott, Mihalopoulos, Erskine, Roberts & Rahman, 2016), without clarification it is not understood whether they included parents of children with physical, psychological, behavioural, genetic or a combination of each DD. This is important as many studies have revealed differences in maternal well-being and perceived parental competence across distinct sub-types of DDs (Pelchat & Lefebvre, 2003; McStay, Trembath & Dissanayake, 2015; Robinson & Neece, 2014; Smith & Cheater, 2013). Thus, limiting the validity and reliability of their concluding results as diagnosis and severity of a child's DD can exacerbate or mitigate the PSOC of parents (Findler, Jacoby & Gabis, 2016; Green, 2007).

Despite the contrast between the prior studies, they did indicate that stress is related to PSOC (Katkic et al., 2017; Ozturk et al., 2014), though, it could be argued that PSOC is associated with stress in a bidirectional style (Katkic et al., 2017). However, it is necessary to further explore this relationship for a better understanding. Additionally, Katkic et al's (2017) study has been supported by some research, suggesting that there may be alternative explanations as to why some parents of children with a DD fare better than parents of TD children (Dieleman et al., 2018; Findler et al., 2016; Hartley & Shultz, 2015; McStay et al., 2015). In relation to this, their research also found that support quality appeared to moderate the relationship between having a child with a DD, PSOC and stress (Katkic et al., 2017). They found marital satisfaction to be a significant protective factor against maternal stress. This could possibly be because marital quality in Western countries has been argued to be a foundation of either stress or support

for parental responsibility (Hartley, Seltzer, Barker & Greenberg, 2014; Robinson & Neece, 2014). Thus, in this case, it might suggest that stable and supportive relationships lessened the stress experienced by mothers of children with a DD and consequently increased their sense of parental competence (Hartley et al., 2014; McStay et al., 2015; Robinson & Neece, 2014). Therefore, highlighting an importance of investigating social support to understanding the impact of raising a child with a DD.

Social Support

An issue within this area of the literature is related to how best define social support (Williams, Barclay & Schmied, 2004). Despite many researchers acknowledging that it involves at least two people in a relationship transaction, the nature of it is still yet to made clear (Lin, Ye, & Ensel, 1999; Wang, 2014; Williams et al., 2004; Zimet, Dahlem, Zimet & Farley, 1988). For example, Lin et al (1999) stated that social support can have a structural property i.e. being part of a community or social network, or a functional property i.e. being instrumental or expressive. More recently, Wang (2014) suggested that social support was the care or help that an individual can perceive, notice or accept from other bodies. There are numerous hypotheses within the literature that have been explored with regard to social support (Lin et al., 1999; Wang, 2014; Williams et al., 2004; Zimet et al., 1988), and whilst these provide valuable information on the construct, it also presents a challenge for research if they do not provide a sufficient and operational definition within their study, to allow valid testing of a single dimension (Sarason & Sarason, 2009). Therefore, for this research, the definition previously stated by Wang (2014) was used. This is because, a feature of his definition includes how individuals ‘perceive’ support and the literature has suggested that

parents who perceive high-quality support have more positive outcomes (McStay et al., 2015; Robinson & Neece, 2014; Zimet et al, 1988).

It is argued that consistent, good quality social support can mediate the association between stress and happiness for parents, with limited or poor quality social support thought to increase their susceptibility to psychological and emotional distress (Cadwgan & Goodwin, 2018; Dieleman, Moyson, De Pauw, Prinzie & Soenens, 2018; Findler et al., 2016; Kiami & Goodgold, 2017; Slattery, McMahon & Gallagher, 2017 Weiss et al., 2013). For instance, Findler et al (2016) asked 191 mothers of children with various disabilities to fill out six questionnaires. After analyses, they found that social support accounted for 7% of the variance between levels of maternal happiness and the type of disability their child had. Although not particularly high, it should be noted that the literature has not determined a distinct score for what is an acceptable minimum variance in this type of research (Abdi, Williams & Valentin, 2013; Field, 2013; Yong & Pearce, 2013). Thus, what is understood from this is that of the mothers raising a child with a disability, those who reported higher levels of social support also tended to report higher levels of happiness. Therefore, it could be argued that social support is a mediating variable that can increase the positive adjustment of parents raising a child with a disability (Cadwgan & Goodwin, 2018; Dieleman et al., 2018; Findler et al., 2016; Slattery et al., 2017). What is also interesting, is that this relationship was also found to be influenced by levels of stress, as parents with higher stress levels reported lower happiness (Findler et al., 2016). This suggests that whilst social support can explain a proportion of the variance between maternal happiness, this was more so the case if mothers reported lower levels of stress. A possible explanation for this may be because when people experience higher

levels of stress they are less trusting and more apprehensive, making it difficult for them to rely on others and hence they perceive that they receive lower levels of support (Aneshensel, 2013; Rueger & Malecki, 2011). This is supported by a plethora of research indicating that parents of children with a disability that report lower levels of stress also tend to report higher levels of perceived social support (Cadwgan & Goodwin, 2018; Dieleman et al., 2018; McStay et al., 2015; Pelchat & Lefebvre, 2003; Robinson & Neece, 2015); indicating that both factors can influence parental happiness and the family as a whole (Findler et al., 2016; Hartley & Shultz, 2015; Jennings, Stagg, Connors & Ross, 1995; Shivers & Kozimor, 2017).

Further, using qualitative methods, Dieleman et al (2018) interviewed 15 parents of children with ASD and found that social support was not characterised by a static and expected behaviour, but rather that it could be divided into sub-themes which each encompassed a different purpose. For example, relational support related to providing love and affection, whilst competence support related to planning and structuring. Referring back, this is not something that Findler et al (2016) incorporated into their study as they used a standardised measurement tool to examine social support as a whole. Whilst they did obtain a high Cronbach's alpha (.93) from their cohort, demonstrating good reliability (Cozby & Bates, 2012), it could be possible that the questions relating to social support did not include options relating to each type of support, which can limit and restrict the responses of participants (Cozby & Bates, 2012; Hyman, Lamb & Bulmer, 2006). Therefore, this could suggest that quantitative methods alone may not sufficiently investigate the influence of social support if it does not provide separate options to explain and corroborate the different attributes of support (Ilias et al., 2018;

McKim, 2017). Though, Dieleman et al's (2018) qualitative research does support quantitative data, indicating that high-quality social support can decrease the impact of stress and negative psychological symptoms for parents raising a child with additional needs, and that inclusive multifaceted support can also promote positive adjustment behaviours (Findler et al., 2016; Hartley & Shultz, 2015; Hodgetts, McConnell, Zwaigenbaum & Nicholas, 2016; Jennings et al., 1995).

In another investigation, Hartley and Shultz (2015) found that both mothers and fathers of children with ASD were at a higher risk for poor psychological wellbeing than parents of children without ASD. Their mixed methods approach revealed that both mothers and fathers differed in what they felt their support needs were and how best those needs were met. Mothers appeared to report higher numbers of support needs than did fathers. This higher number of support needs disclosed by mothers could partly reflect a larger role in childcare, whilst the lower number of support needs of fathers may be explained by a lesser involvement in intervention services (Howard et al., 2011; Oliveira, 2018; Phares, Fields & Binite, 2006 Raley et al., 2012). Hartley & Shultz (2015) demonstrated that parents raising a child with a disability displayed lower psychological wellbeing scores than those raising a TD child (Findler et al., 2016; McStay et al., 2015; Robinson & Neece, 2014) and perceived support and how it was actioned differently, consequently supporting Dieleman et al's (2018) notion that social support is a multifaceted concept. Therefore, it is argued that future research needs to acknowledge this prior to investigating the impact of social support, to fully understand its influence on parents of children with disabilities.

Hope

There is an abundance of evidence demonstrating the negative impact of raising a child with a disability on parental mental health (Dieleman et al., 2018; Findler et al., 2016; Hartley & Shultz, 2015; Katkic et al., 2017; McStay et al., 2015; Padden & James, 2017; Pelchat & Lefebvre, 2003; Robinson & Neece, 2014; Smith & Cheater, 2013; Yamaoka et al., 2015). However, limited research has explored what parents may learn or gain from this experience, or about the beneficial aspects of their caregiving role (Cless, Nelson Goff & Durtschi, 2018; Schwartz & Hadar, 2007). Beyond stress levels and psychological burden, it is also important to consider parental attitude as a factor that could buffer adversity (Cless et al., 2018). One way this could be done is by looking at hope. Snyder (2002) defined hope as "a positive motivational state that is based on an interactively derived sense of successful agency (goal-directed energy) and pathways (planning to meet goals)" (p. 250). Research has suggested that hope is related to adaptive coping, facilitating the process of adaption and positive psychological outcomes (Cless et al., 2018; Illum, Bonderup & Gradel, 2018; King et al., 2006; Ogston, Mackintosh & Myers, 2011; Reif, Bugos, Giarelli, Bernhardt & Spinner, 2017; Schwartz & Hadar, 2007; Snyder, 2002). This is possibly because individuals with high levels of hope are flexible thinkers, motivated to mentally prepare plausible alternate routes to recover from unfavourable circumstances (Snyder, 2002). This type of versatile thinking could support parents that are raising a child with a disability to overcome difficult situations that they might face.

Of the extensive research that has explored the wellbeing of parents raising a child with a disability, only a small number of studies have looked at the influence of hope on psychological health (Cless et al., 2018; Ogston et al., 2011).

In Ogston et al's (2011) study, 259 mothers of children with down's syndrome (DS) or ASD were assessed on measures of hope and worry. They found that mothers who reported higher hope also reported lower worry, but that overall, mothers of children with ASD had lower levels of hope and greater worry than mothers of children with DS. This could be explained in terms of prognosis. For instance, with DS, on the whole, parents are aware of the possible trajectories of their child's developmental outcomes (Cless et al., 2018). On the other hand, regarding ASD there is no dependable method to predict a child's developmental outcomes; some children with ASD make considerable progress whilst others do not (King et al., 2006; Ogston et al., 2011). Hence, after receiving a prognosis for their child it is natural for parents to worry, especially if they cannot discern the impact this will have, which may negatively affect their ability to plan and achieve their goals; a previously discussed principle of hope (Snyder, 2002).

Cless et al (2018) found that hope was positively correlated with dyadic adjustment and coping in a sample of 351 mothers raising a child with DS. Mothers with higher levels of hope appeared to adjust better than those with lower levels of hope. Hope appeared to be a protective factor against psychological distress for mothers of children with disabilities (Cless et al., 2018; Ogston et al., 2011). This is supported by a qualitative study by King et al (2006), who looked at families of children with ASD and DS. They shared the importance of hope to adapt over time and gain a sense of empowerment over their situation. Interestingly, they also noted that families were given hope when they perceived receiving appropriate social support; including stories of successful experiences. This suggests that whilst hope can impact the psychological wellbeing of parents of children with a disability, social support also plays a part in this relationship; a

partial mediation (Hayes, 2017). Whilst providing valuable information on the role of hope in parental wellbeing, the emphasis on DS amongst many of the aforementioned studies limits how this data could be generalised to parents of children with different disabilities (Cless et al., 2018; King et al., 2006; Ogston et al., 2011). This is because, parents of children with DS are said to have an "advantage" over parents of children with other intellectual disabilities, as DS is a genetic disorder which predisposes children to specific aetiology-related behaviour, which can lessen parental stress and allow for greater parenting rewards (Esbensen & Seltzer, 2011; Mitchell, Hauser-Cram & Crossman, 2015). Thus, as hope is recognised as a significant factor in the adjustment of parents of children with a disability, further investigation is needed to understand how it may contribute to psychological wellbeing.

The present study

In sum, research has studied the impact of raising a child with a disability on parental mental health. However, a vast amount of the research has focused on the negative effects, such as parental stress and burden (Dieleman et al., 2018; Findler et al., 2016; Hartley & Shultz, 2015; Katkic et al., 2017; McStay et al., 2015; Padden & James, 2017; Pelchat & Lefebvre, 2003; Robinson & Neece, 2014; Smith & Cheater, 2013; Yamaoka et al., 2015). The present study sought to investigate a more inclusive profile of parents raising children with a disability, combining multiple domains that have been studied separately within the literature. Accordingly, guided by the literature in this area, the current study had five hypotheses: (1) Parents raising a child with a disability, including ASD, would report higher levels of stress than parents raising a TD child. (2) Parents raising a child with a disability or ASD would report lower levels of parental competence

than parents raising a TD child. (3) Parents raising a child with a disability or ASD would perceive receiving less social support than parents raising a TD child. (4) There would be a difference in hope levels between parents of TD children and parents of children with disabilities, including ASD (5) There would be a predictive effect of social support, parental sense of competence, hope and parental type on parental stress levels.

Method

Participants

Initially, there were 209 participants recruited using a volunteer sample; however, some cells had large amounts of missing data and were necessarily removed, leaving a total of 184 participants remaining. The age range across participants varied from 22 to 85 and the mean age of participants was 39.36 (*SD* = 10.45). An inclusion criterion for this study was that participants must be aged 18 or over. This is because, participants aged under 18 with children are classed as teen parents, and research has found that teen parents, even of typically developing children have been shown to face additional problems when raising a child (Cook & Cameron, 2017; Stiles, 2008). The sample contained both male and female participants, with 20 fathers and 164 mothers. The participants were split as follows: 127 participants were parents of children with a disability and 57 participants were parents of TD children. As recruitment took place online, there was a wide range of socioeconomic backgrounds across individuals. Ethical approval was given by the University of Chester Psychology Department Ethics

Committee (see Appendix A). Furthermore, each participant was treated in accordance with the BPS ethical guidelines (The British Psychological Society., 2010), for example informed consent was obtained prior to the start of the study and individuals were informed of their right to withdraw.

Measures

An online questionnaire was used to collect data, which contained five sections. The first section was a demographics component containing questions that described the participant, such as sex and age, and additional information relating to their current situation regarding home life and children. The subsequent four sections included assessment scales for stress, parenting sense of competence, social support and levels of hope.

The perceived stress scale (PSS) (Cohen, Kamarck & Mermelstein, 1983). A 10-item five-point self-report measure used to assess parental stress levels. Each participant was asked to rate ten statements based on how they best described their current circumstances in the present moment. To provide an example, one statement used in this scale: “In the last month, how often have you felt nervous and stressed?” would be rated from “0 = Never” to “4 = Very often”. The total score was calculated by combining the scores of each question, after reverse scoring any negative questions, with higher scores indicating increased stress. The PSS has been implemented globally to assess levels of stress with successful application being noted on numerous occasions, indicating that the scale is efficiently unidimensional when assessing parental stress (Masa’Deh, Bawadi, Saifan & AbuRuz., 2015) and across diverse population samples

(Denovan, Degnall, Dhingra & Grogan., 2017; Lee, 2012; Wu & Amtmann., 2013). Focusing on reliability, a scale is deemed to be internally consistent if it scores between .70 and .95 in a Cronbach's alpha test (Field., 2013; Tavakol & Dennick, 2011). In the sample of the current study, the scale received a Cronbach's alpha of .71, demonstrating a good level of internal consistency.

The parenting sense of competence scale (PSOS) (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989). A 17-item self-report measure used to examine participant beliefs of their own ability in the parenting role on two dimensions: satisfaction and efficacy. In terms of satisfaction, the questions relate to parental anxiety, frustration and motivation, whilst questions surrounding efficacy examines competence, capability and problem-solving in a parental role. Participants were asked to rate each statement on how it best relates to their life from "1 = strongly disagree" to "6 = strongly agree". One example of a positively scored item: "Being a parent is manageable and any problems are easily solved". Negatively worded questions were reverse scored before totalling. For this research, the measure was used as an overall parenting sense of competence score, thus a total score was calculated, and higher scores related to higher feelings of parental competency (Gibaud-Wallston & Wandersman., 1978, cited in Johnston & Mash., 1989). Historically, the PSOS has had great success generalising across populations (Karp, Lutenbacher & Wallston., 2015; Ohan, Leung & Johnston., 2000), highlighting its sufficient convergent and discriminant validity (Hurley, Huscroft-D'Angelo, Trout, Griffith & Epstein., 2014) and it has also received recognition for its gender applicability when administered individually to mothers and fathers (Trahan & Cheung., 2016).

Within the current sample, the scale was also found to have a high level of validity as determined by a Cronbach's alpha of .75.

The adult dispositional hope scale (AHS) (Snyder et al., 1991). A 12-item self-report scale used to measure cognitive levels of hope. According to Snyder et al (1991), hope is defined as a positive motivational state which is based on specific ways of thinking; pathway thinking, which highlights perceived ability to create routes towards achieving personal goals, and agency thinking, which is the perception of one's own ability to generate and nurture the use of these routes. Four items from the scale make up the agency or "goal directed" subscale, four items construct the pathways or "planning to accomplish goals" subscale and the remaining four items are filler questions. Participants were asked to rate each statement as it currently related to them on an eight-point Likert-type scale ranging from "1= definitely false" to "8= definitely true". Previously, the scale has fared well in translation and validation amongst different countries, samples (Ekas, Pruitt & McKay, 2016; Espinoza, Molinari, Etchemendy, Herrero, Botella & Rivera., 2017; Oliver, Tomas, Montoro- Rodriguez., 2017) and methodologies (Vernberg & Snyder., 2005). Hope was assessed overall and in terms of each subscale, with higher scores indicating higher levels of hope. The overall Cronbach's alpha for the scale in the study sample was .87, a high score indicating good reliability. This was calculated by summing the four items from the pathway subscale and the four items from the agency subscale, to create an overall hope score (Snyder et al., 1991). Additionally, high levels of internal consistency were found in both the pathway subscale (a= .77) and the agency subscale (a= .80). Hence, the scale was accepted as a reliable measure of hope.

The multidimensional scale of perceived social support (MSPSS) (Zimet, Dahlem, Zimet & Farley., 1988). A 12-item self-report scale that typically assesses participant relationships with family, friends and a significant other. As an assessment tool, this scale has demonstrated itself to be a solid and sensitive researching instrument across vulnerable samples when discriminating between sources of support and the impact that they have (Stewart, Umar, Tomenson & Creed., 2014; Zimet et al., 1988). As stated, the MSPSS comprises of three sub-scales, being 'family', 'friends' and 'significant other', though for this study these subscales were adapted to assess 'family', 'significant other' and 'access to services'. To reiterate, 'access to services' replaced the 'friends' subscale of the existing MPSPSS scale (see Appendix B). Amongst other reasons, this is because research has stated that access to services is a beneficial resource, as professional services can teach parents appropriate skills to support their child's developmental needs (Kaiser, Terry & Hancock, 2003). "Access to services" related to the important rights of access to everyday support services that all parents are entitled to, to ensure their everyday living quality is at its best possible level (The Equality Act, 2010). This required adapting questions in the MSPSS that related to the 'friends' subscale. For example, one question in the 'friends' subscale read "I have friends with whom I can share my joys and sorrows". However, the revised question in this instance read "I can easily access a support service that I am able to share my feelings with". The question overall was worded differently though still focused on typical feelings that are experienced by parents. A score for each subscale was created by summing all the relevant questions and then all the responses were combined for a total support score. Higher scores revealed higher perceived social support. High levels of internal consistency were

found for all three subscales of the measure; significant other (a = .96), family (a= .95) and access to services (a= .95). Social support as an overall concept also revealed high internal consistency, as demonstrated by a Cronbach's alpha of .93.

In addition to reliability analyses, a Principle Components Analysis (PCA) was used to assess the validity of the four items relating to the subscale "access to services". Previously, the scale has shown good validity across different population samples for all the original subscales; friends, family and significant other (Stewart, Umar, Tomenson & Creed, 2014; Wang, Wan, Huang & Kong, 2017). Therefore, only the "access to services" subscale was tested as this was used to replace the "friends" subscale. The Kaiser-Meyer-Olkin (KMO) test indicated that the sample was adequate for PCA analysis, as KMO = .79, a satisfactory value (Field, 2013; Pallant, 2016), and Bartlett's test shown a necessary significant result (Field, 2013; Pallant, 2016). An initial analysis revealed one factor had an eigenvalue over Kaiser's criterion of 1 and explained 86.09% of the variance. The scree plot supported this finding and showed one distinct inflexion that would justify retaining only one factor. As intended, these four items appeared to measure only one factor. Table 1 below shows the factor loadings. All items had factor loadings above .4, suggesting that each item contributed well to one main factor (Fields, 2013; Yong & Pearce, 2013).

Table 1: Factor Loadings of the 4 items in the "Access to Services" subscale of the MSPSS.

Item number	Factor Loading
6	.92
7	.95
9	.93
12	.91

Procedure

Following approval from the University of Chester Ethical committee a request for participants was posted onto the social media site Facebook, as research has suggested that this type of recruitment strategy is more time-effective than traditional strategies and can also attract hard-to-reach populations (Kayrouz, Dear, Karin & Titov., 2016; Whitaker, Stevelink & Fear., 2017). This involved posting onto specific group pages dedicated to parents. Individuals who responded to this post were given a link that would direct them to the first stages of the questionnaire. This included an information sheet (see Appendix C), which described the research in more detail. Following this, participants would move on to complete the assessment measures of the questionnaire. Their continuation with the study acted as their consent to take part. The average time needed to complete the study was 10-15 minutes. Once all responses were submitted, participants were presented with a completion receipt, containing a debrief form (see Appendix D).

After the data collection, it was necessary for some of the raw data to be clarified to prepare it for analyses. For instance, the range of stated disabilities between participants was quite wide. Of the parents of children with disabilities, 67 participants stated their child had a diagnosis of ASD and 60 participants listed a range of other diagnosed disabilities for their children. Due to the diversity across these additional disabilities, it was not possible to separate them into specific groups for analysis. Therefore, it was decided that these participants would form a single group labelled as “grouped conditions” for further analysis to be conducted. This created three distinct groups: “ASD”, “Grouped Conditions” and “Comparison”. The first group consisted of parents who stated that their child was diagnosed with Autism Spectrum Disorder, including comorbid diagnoses (PCASD). The second

group was created due to the diversity amongst diagnoses and was comprised of parents with children who did not have ASD (PCGC). Finally, the “Comparison” group consisted of parents with typically developing children.

Finally, once enough participant responses were obtained, the data was transferred for analysis from Bristol Online Surveys to the statistical software SPSS. There were separate data sheets for computing each hypothesis. Additionally, for the final hypothesis, PCASD and PCGC were combined to make an overall group of disabilities to analyse and were labelled 1, whilst parents of typically developing children were labelled as 2.

Design and Analysis

The research carried out for this study was cross-sectional and between-subjects in design. The dependent variable was stress. The independent variables were hope, parental sense of competence, social support and parental type. Statistical analyses were conducted to test all the hypotheses previously stated. This included using a one-way ANOVA, with three levels (ASD, Grouped Conditions, Control) to determine differences across groups. Though when indicated that the assumption of homogeneity was not met, the Welch’s *F*-ratio was reported. Following this, the data was analysed using Spearman’s correlation analysis and hierarchical multiple regression to ascertain differences between the groups. The alpha level was set at $p<0.05$.

Results

The first analysis looked at differences in stress between PCASD, PCGC and the comparison. First, the result of a Shapiro-Wilk (S-W) test showed that the sample distribution of parents with typically developing children and PCGC were not statistically significant from a normal distribution (SW= .98, n= 52, *p*= .62; SW= .98, n= 49, *p*= .55, respectively). However, the scores of PCASD deviated from normality (SW= .93, n= 42, *p*= .01). Additionally, a Levene's test revealed evidence for significant deviation from homogeneity of variance between the groups $F(2, 140) = 4.94$, $p < .01$. Table 2 outlines the means (SD's) for overall stress levels between PCASD, PCGC and the Comparison. Further inspection revealed that PCASD reported the highest stress, whilst parents of typically developing children reported the lowest stress; this was found to be significant, Welch's $F(2, 89.12) = 12.68$, $p < .001$, $\omega^2 = .41$. Post hoc comparisons using the Games-Howell test indicated that there was a significant difference reported between the scores of PCASD and the comparison ($p < .001$), and between PCGC compared to the comparison group ($p < .01$). No other comparisons were found. Specifically, these results suggested that parents raising a child with a disability, regardless of the diagnosis, experienced higher stress levels than parents raising a TD child.

Table 2: Means (SD's) for stress, parenting sense of competence, support and hope between parents of typically developing children, parents of children with ASD and parents of children in grouped conditions.

	ASD	GC	Comparison
Stress	34.64 (4.61)	32.57 (3.66)	29.19 (5.88)
PSOC	62.44 (9.59)	62.08 (8.31)	71.50 (11.08)
Social Support	51.19 (16.33)	50.16 (15.74)	62.25 (15.54)
Significant other	21.74 (6.67)	20.84 (6.79)	23.50 (5.63)
Family	17.53 (7.39)	18.56 (7.34)	21.65 (6.78)
Access to services	11.91 (7.50)	10.76 (6.05)	17.10 (6.47)
Hope	40.33 (9.21)	38.10 (12.32)	44.85 (8.63)
Agency	18.84 (5.63)	17.64 (7.00)	21.77 (5.20)
Pathway	21.49 (5.11)	20.46 (5.94)	23.08 (4.22)

In a similar manner, hypothesis two stated that parents raising a child with a disability, including those whose children have ASD, would report lower levels of perceived parental competence than parents raising a TD child. The result of the S-W test showed that the sample distribution of the comparison group and PCASD were not statistically significant from a normal distribution, though PCGC deviated from normality (SW = .97, n = 52, p = .27; SW = .97, n = 41, p = .43; SW = .95, n = 49, *p* = .04, respectively). Additionally, the Levene's test also revealed evidence for significant deviation from homogeneity of variance across the three groups, *F*(2, 139)

= 3.57, $p < .05$). There was a significant effect of parental type on parental sense of competence scores at the $p < .001$ level for the three conditions, Welch's $F(2, 89.82) = 13.27$, $p < .001$, $\omega^2 = .40$. Post hoc Games-Howell tests revealed significant differences between PCASD and the comparison ($p < .001$) and between PCGC and the comparison ($p < .001$). The results, as shown in Table 2, suggested that there was higher perceived parental sense of competence in parents raising a typically developing child compared to PCASD and PCGC.

The next goal of the current study was to determine the perception of social support for parents raising a child with a disability and parents raising a TD child. The S-W test showed that the sample distribution of parents of TD children deviated from normality (SW = .93, n = 52, $p < .01$), though PCASD (SW = .98, n = 43, $p = .75$) and PCGC (SW = .98, n = 50, $p = .55$) were not statistically significant from a normal distribution. The Levene's test revealed no evidence for significant deviation from homogeneity of variance, $F(2, 142) = .16$, $p = .85$. This was also the case for each support subscale; "significant other" ($F(2, 142) = 1.01$, $p = .37$), "family" ($F(2, 142) = 1.39$, $p = .25$) and "access to services" ($F(2, 142) = 2.42$, $p = .09$). The ANOVA revealed that the comparison group perceived higher levels of overall social support than did PCASD and PCGC, which was found to be significant, $F(2,142) = 9.01$, $p < .001$, $\eta^2 = .11$. Post hoc Tukey tests showed that the mean score of the comparison group was significantly differently than the score for PCASD ($p < .01$) and PCGC ($p = .001$). The results indicated that parents of typically developing children reported higher levels of perceived social support than did PCASD and PCGC. There were no other significant comparisons found.

For the "significant other" subscale, the S-W test showed that the scores from the comparison group, PCASD and PCGC all deviated from normality (SW = .79, n =

52, $p < .001$; SW = .84, n = 43, $p < .001$; SW = .89, n = 50, $p < .001$, respectively). The mean scores of the groups suggested that the comparison group perceived higher levels of social support from a significant other than PCASD and PCGC. This difference was not found to be significant, $F(2, 142) = 2.31$, $p = .10$, $\eta^2 = .03$, hence no further post hoc tests were run.

The second investigated subscale of social support was “family”. The S-W test again showed that the scores from the comparison group (SW = .83, n = 52, $p < .001$), PCASD (SW = .92, n = 43, $p < .01$) and PCGC (SW = .92, n = 50, $p < .01$) were statistically significant from a normal distribution, indicating that all groups deviated from normality. The results of the ANOVA found significant differences between the groups, $F(2, 142) = 4.38$, $p < .05$, $\eta^2 = .06$. Inspection of the means indicated that PCASD perceived the lowest amount of familial support and the comparison perceived the most support. Further post hoc Tukey tests found a significant difference between the comparison group and PCASD ($p < .05$), suggesting that PCASD perceived significantly lower familial support than the comparison group. No other comparisons were found.

Finally, the last subscale of social support was “Access to Services”. The sample distribution of the comparison group was not statistically significant from a normal distribution (SW= .97, n = 52, $p = .26$), though the distribution of PCASD (SW = .88, n = 43, $p < .001$) and PCGC (SW = .90, n = 50, $p = .001$) significantly deviated from normality. The ANOVA investigated differences between the groups, and revealed that the means differed significantly, $F(2, 142) = 13.04$, $p < .001$, $\eta^2 = .16$. This, alongside the mean scores, indicated that PCGC perceived the lowest amount of support from accessing services, though they were very closely followed by PCASD. Post hoc Tukey tests found significant differences between the comparison

and PCASD (p = .001), and between the comparison and PCGC (p < .001). Therefore, suggesting that the comparison group perceived that they received significantly higher levels of support from services than PCASD and PCGC.

The fourth hypothesis stated that there would be a difference in hope levels between parents of TD children and parents of children with disabilities. The S-W test for the sample distribution of the comparison group (SW = .96, n= 52, p= .06), PCASD (SW = .97, n = 43, p= .42) and PCGC (SW = .98, n = 50, p= .69) was not found to be statistically significant from a normal distribution. Though, the Levene's test revealed evidence for deviation from homogeneity of variance, $F(2, 142) = 5.33$, $p < .01$. Nevertheless, the effect of parental type on hope levels was found to be significant, Welch's $F(2, 91.67) = 5.99$, $p < .01$, $\omega^2 = .25$. The data revealed parents in the comparison group reported the highest amount of hope, whilst PCGC reported the least. Post hoc Games-Howell tests found that the comparison group had significantly higher hope levels than PCGC (p < .01) and PCASD (p < .05).

For the "agency" subscale, the S-W found that PCASD (SW = .96, n = 43, p = .15), PCGC (SW = .97, n = 50, p = .32) and the comparison group (SW = .97, n = 52, p = .20) all met the assumption of normality. Additionally, a Levene's test demonstrated no evidence for deviation from homogeneity of variance, $F(2, 142) = 2.86$, $p = .06$. Analyses revealed a significant effect of parental type on agency hope, $F(2, 142) = 6.38$, $p < .01$, $\eta^2 = .08$. Parents of TD children had the highest score of agency hope, followed by PCASD, and PCGC reported the lowest. Post hoc Tukey tests found that the comparison group had significantly higher levels of agency hope than PCASD (p = .05) and PCGC (p < .01).

Finally, the “pathway” subscale of hope was investigated. The S-W test showed that the sample distribution of the comparison group deviated from normality (SW = .94, n = 52, $p < .01$), though PCASD (SW = .98, n = 43, $p = .69$) and PCGC (SW = .98, n = 50, $p = .69$) were not statistically significant from a normal distribution. The Levene’s test did indicate evidence from homogeneity of variance, $F(2, 142) = 4.33$, $p = .02$. The analysis found that the comparison group reported higher pathway hope than PCASD and PCGC; a finding that was statistically significant, $F(2, 90.32) = 3.56$, $p < .05$, $\omega^2 = .17$. Post hoc Games-Howell tests revealed that the comparison group had significantly higher pathway hope scores than PCGC ($p < .05$).

The final hypothesis stated that there would be a predictive effect of social support, PSOC, hope and parental type on parental stress levels. To do this, PCGC and PCASD were combined to form one “parental type” group, to compare parents of children with disabilities (including ASD) to the comparison group. Parental type referred to each group in the analysis: the comparison group and parents of children with a disability (inclusive of ASD). Bivariate correlational analyses were conducted to investigate the relationship between stress, perceived support from a significant other, family and access to services, parental sense of competence, agency hope, pathway hope and parental type. To clarify, subscales of social support and hope were used for a more in-depth analysis. The results are illustrated in Table 3.

Table 3: Spearman's correlation of variables under examination (N in brackets).

	Stress (182)	Sig Other (182)	Family (182)	Services (182)	PSOC (177)	Agency (182)	Pathway (181)	Parental Type (182)
Stress		-.17*	-.32**	-.22**	-.47**	-.38**	-.31**	-.39**
Sig Other			.67**	.25**	.25**	.21**	.22**	.19**
Family				.37**	.26**	.25**	.16*	.25**
Services					.27**	.18*	.12	.33**
PSOC						.48**	.48**	.36**
Agency							.67**	.28**
Pathway								.20**
Parental Type								

Key: *Correlation is significant at the 0.05 level, **Correlation is significant at the .01 level.

A Spearman's rank-order correlation was run to determine the relationship between the variables. There was a significant negative relationship between stress and parental type. This indicated that raising a child with a disability, including ASD, was related to high levels of stress. Similarly, there were significant negative relationships between stress and perceived support from a significant other, family and access to services, parental sense of competence, agency hope and pathway hope. Increased levels of stress appeared to be related to decreased levels of parental sense of competence, hope and perceived social support.

Following this, a hierarchical multiple regression analysis was conducted to test whether any variables could predict stress. The assumptions to run a multiple regression were all met (see Appendix E). The criterion variable was stress and the predictor variables, in order of entry were perceived support from a significant other, family support, access to services, parental sense of competence (PSOC), agency hope, pathway hope and parental type. The results from the analysis are shown in Table 4.

Table 4: Summary of a hierarchical multiple regression: perceived support, parental sense of competence, hope and parental type as predictors of stress.

Model	ß (p)	Adj R sq	*F(p)*	*R²Δ*	*FΔ(p)*
Step 1		.10	7.64 (<.001)	.12	
Significant Other	.07 (.46)				
Family Support	-.32 (<.01)				
Access to Services	-.12 (.14)				
Step 2		.32	21.23 (<.001)	.21	54.81 (<.001)
Significant Other	.14 (.08)				
Family Support	-.28 (<.01)				
Access to Services	-.01 (.98)				
PSOC	-.50 (<.001)				
Step 3		.33	15.66 (<.001)	.03	3.36 (.04)
Significant Other	.16 (.05)				
Family Support	-.26 (<.01)				
Access to Services	-.01 (.88)				

PSOC	-.41 (<.001)				
Agency Hope	-.17 (.05)				
Pathway Hope	-.02 (.82)				
Step 4		.37	15.69 (<.001)	.04	10.55 (<.01)
Significant Other	.15 (.05)				
Family Support	-.25 (<.01)				
Access to Services	.04 (.58)				
PSOC	-.36 (<.001)				
Agency Hope	-.14 (.12)				
Pathway Hope	-.03 (.69)				
Parental Type	-.22 (<.01)				

The regression at step one was found to be statistically significant ($F(3, 172) = 7.64$, $p < .001$), indicating that perceived support from a significant other, family and access to services were good predictors of parental stress. The direction of the regression indicated that lower perceived familial support and limited access to services predicted higher reported stress, though interestingly, higher perceived support from a significant other appeared to predict higher stress. When looked at individually, family support appeared to significantly predict parental stress, though support from a significant other and access to services were not found to be significant predictors. Despite this, together these variables were able to significantly predict 10% of the variance between the comparison group and parents of children with a disability.

At step two, parental sense of competence was added into the regression. As an individual predictor, PSOC was shown to significantly predict parental stress ($p < .001$). The direction indicated that higher levels of PSOC predicted lower levels of stress. The inclusion of PSOC at this step increased the percentage of variance predicted in stress levels to 32%, which was also deemed significant ($F(4, 171) = 21.23$, $p < .001$).

Following this, the hope subscales (agency and pathway) were added into the regression. It appeared that stress levels were not significantly predicted by agency or pathway hope as individual predictors. However, the direction did suggest that lower levels of reported agency and pathway could predict higher levels of stress. The inclusion of these variables at this step increased the percentage of variance predicted to 33%, this was found to be significant ($F(6, 169) = 15.66$, $p < .001$).

Finally, at step four parental type was included in the regression analysis. As previously stated “parental type” related either to raising a child with a disability, inclusive of ASD, or raising a TD child. The direction indicated that raising a child with a disability was a significant predictor of higher reported stress. Following the inclusion of parental type at this step, it appeared that higher perceived access to services actually predicted higher stress in parents, though this was not a significant change. Of all the variables, agency hope, pathway hope, perceived support from a significant other and access to services were not found to be significant individual predictors of the reported parental stress. On the other hand, PSOC, perceived familial support and parental type were all significant individual predictors of stress. Interestingly, the strongest predictor of stress within this sample was PSOC suggesting that, overall, low levels of perceived parental competence could predict higher levels of stress. This was closely followed by parental type and then family support. At this stage, the variables together explained 37% of the variance in stress scores, which was found to be significant ($F(7, 168) = 15.69$, $p < .001$).

Discussion

The main aim of the current study was to investigate whether there were any differences between parents raising a TD child and parents raising a child with a disability or ASD regarding their parenting stress. Additional analyses were also conducted to explore the potential effects raising a child with a disability can have on parental sense of competence, perceived social support and hope. Firstly, hypothesis one which stated that parents raising a child with a disability, including ASD, would report higher levels of stress than parents raising a TD child, was

accepted. The second hypothesis was also supported, finding that PCASD and PCGC reported lower levels of parental competence than parents raising a TD child. Hypothesis three was also supported as PCASD and PCGC reported significantly lower perceived support, overall and in each subscale, when compared to the comparison. Hypothesis four found that parents of TD children reported higher levels of hope than did PCASD and PCGC, both overall and in each subscale of hope and was therefore supported. Finally, a multiple regression revealed that whilst parental type, PSOC and perceived familial support were significant predictors of reported stress in parents, levels of hope, perceived support from a significant other and access to services were not able to significantly predict stress. Therefore, hypothesis five that stated there to be a predictive effect of parental type, PSOC, social support and hope on parental stress levels, was partially supported.

Stress Levels in Parents raising a child with disabilities

Large amounts of research have documented that parents of children with disabilities face additional challenges and are more susceptible to stress than parents of TD children, indicating that the relationship between these two variables has remained a consistent and prominent issue (Bourke-Taylor et al., 2013; Cadwgan & Goodwin, 2018; Estes et al., 2013; Feizi et al., 2014; Green, 2007; Hartley & Shultz, 2015; Padden & James, 2017; Pelchat & Lefebvre, 2003; Yamaoka et al., 2015). Specifically, the current findings expanded on previous research by separating child disability to look more clearly at ASD when compared to grouped conditions as well as TD children. Parents of children with ASD and GC both reported significantly higher levels of stress than the comparison group. Thus, the results from the present study support past research, in that raising a child with a disability is negatively associated with parental stress levels (Bourke-Taylor et al.,

2013; Cadwgan & Goodwin, 2018; Estes et al., 2013; Green, 2007; Hartley & Shultz, 2015; Padden & James, 2017; Pelchat & Lefebvre, 2003; Yamaoka et al., 2015). This disputes Katkic et al's (2017) findings that parents of TD children reported higher amounts of stress than did parents of children with DD. Interestingly, such conflicting findings could be explained by distinctions between parental perception. It is possible that parents of children with a disability perceived their stress levels differently to parents of TD children, as their experiences may have created opportunities for them to identify adaptive coping strategies for stress (Hartley & Schultz, 2015; Padden & James, 2017). Therefore, the contrasting findings between the current study and Katkic et al's (2017) study may be explained in terms of external variables, as neither study discussed investigating whether any parents had found and implemented effective coping techniques to control their stress levels. Hence, future research would benefit from investigating the impact of positive coping strategies to fully understand the how they support parenting challenges.

Additionally, to the best of our knowledge, there are only a minimal amount of single studies that compare parental stress when raising a child with autism against parents of children with a variety of disabilities, though much of this research indicated that PCASD reported significantly more stress than PCGC (Dumas, Wolf, Fisman & Culligan, 1991; Valicenti-McDermott et al., 2014). Within the current study, the direction of the scores between PCASD and PCGC concurs with previous literature, suggesting that PCASD experience greater levels of parenting stress than do parents of children with other disabilities, though this was not found to be significant. However, non-significant result should be evaluated cautiously, as it could be explained by the capacity of the measure. Whilst the PSS (Cohen et al., 1983) is an efficient and popular measure to assess stress levels across samples

(Denovan et al., 2017; Lee, 2012; Masa'Deh et al., 2015; Wu & Amtmann., 2013), it was only used to determine the perceived stress of parents within the last month of their life, which does not account for differences in life circumstances. For instance, more recent research has shown that parenting a child with a disability, inclusive of ASD, creates all-encompassing situations, stating that whilst there are stressful circumstances for these parents their experiences also elicit personal growth and confidence (Cless et al., 2018; Green, 2007; Schwartz & Hadar, 2007). As previously stated, confidence in parenting has been associated with lower stress in parents of children with disabilities (Katkic et al., 2017; Ozturk et al., 2014). Therefore, the results from the measure may vary dependent on the time that it was issued; if parents had been dealing with their child's disability for a considerable amount of time this would more likely lessen parental stress, as they may be more knowledgeable and confident in caring for their child (Katkic et al., 2017; Ozturk et al., 2014). Thus, it is possible that using the measure across numerous time-points would yield different, significant results in future studies.

Parental sense of competence (PSOC)

The second goal of this study was to investigate the relationship between raising a child with a disability and perceived parental sense of competence. The results demonstrated that both PCASD and PCGC differed significantly from the comparison, suggesting that parents raising a TD child tended to have higher levels of overall PSOC. These findings are congruent with previous research that has found low self-perceived parental sense of competence in parents caring for a child with a disability, inclusive of ASD (Craig et al., 2016; Ozturk et al., 2014). Lower perceived parental efficacy in parents of children with a disability can be a result of responding to the behavioural needs of their child, as these are often more challenging than a

typically developing child, which can cause considerable stress and produce additional difficulties for parents when trying to fulfil their role (Craig et al., 2016). This relates to the findings of Ozturk et al (2014) who found that parents who reported greater stress in caring for their child with a disability also reported lower levels of perceived parental competence. Though, the nature of this and previous studies have not clarified whether it is the PSOC that influences the stress of parents, or whether parental stress impacts PSOC; it could be that this relationship is indeed bidirectional, as suggested earlier in this study (Katkic et al., 2017). Nonetheless, the results of the current study do reveal that both PCASD and PCGC reported lower levels of PSOC and higher levels of stress than the comparison, though further exploration would be needed to understand the complex relationship between these variables. However, these findings combined with the previous literature indicate that professional bodies would benefit from addressing issues in both PSOC and parental stress to more effectively support parents raising a child with any disability (Craig et al., 2016; Ozturk et al., 2014; Stuttard et al., 2016).

Much of the prior literature in this area tends to focus on comparing outcomes of parents raising a child with a disability to parents raising a TD child (Craig et al., 2016; Hartley & Shultz, 2015; Katkic et al., 2017; Padden & James, 2017). Thus, for further investigation the current study compared PSOC scores of PCASD against PCGC, to inform the literature about differences in PSOC when comparing ASD to other disabilities. This revealed extremely little difference between the mean scores of PCASD and PCGC, which was not found to be significant. This is interesting because the characteristics of ASD, compared to other disabilities, tend to differ dramatically amongst diagnosis which can limit parents' ability to prepare for their experience (Padden & James, 2017). Thus, it may be possible that the current data

may be a result of small sample size, or that the parental sense of competence amongst PCASD compared to parents of children with other disabilities needs to be explored using more sophisticated and intricate techniques. Accordingly, this prompts cause for further research in this area, possibly incorporating qualitative methods to elaborate on questions that are more general, therefore allowing differences to be identified between PCASD and parents of children with other disabilities.

Social Support

There is a lot of discussion in the literature about the role of social support for parents raising a child with a disability, though much of it highlights that the perception of social support is a resource that can encourage them adjust to and accept their circumstances (Cadwgan & Goodwin, 2018; Dieleman et al., 2018; Findler et al., 2016; Slattery et al., 2017). The current study found that PCGC perceived the lowest amount of social support, followed by PCASD, which significantly differed from the comparison group who reported the highest perceived support. Research has suggested that parents reporting higher levels of perceived social support also tend to report higher levels of happiness and lower levels of stress (Findler et al., 2016; Katkic et al., 2017), yet within this sample PCASD reported the highest levels of stress, despite reporting higher levels of perceived social support than PCGC. An explanation for this could be the amount of social support received by parents relative to when it is needed. Research has shown that whilst social support can be perceived as available to respondents, when this is compared to measuring instances of received social support there is a discrepancy (Melrose, Brown & Wood, 2015). This may be because the type of support parents actually require is not what is available to them, though their perceived support

system is of high-quality (Hartley & Shultz, 2015; Kiami & Goodgold, 2017). Thus, within the current study PCASD may have perceived more social support than PCGC, but the support they received may not have been what was needed to better their circumstances, causing increased levels of stress. Future research should look at including assessments of received social support of PCASD and other disabilities, as this could have implications with how to improve the efficiency of support systems for these parents.

The next part of this research goal, regarding perceived support from a significant other, showed no significant differences between PCASD, PCGC and the comparison. This contrasts a vast amount of prior research, including the theoretical model of parenting determinants which highlights spousal relationships as one of the most important sources of support for parents (Belsky, 1984; Findler et al., 2016). Recently, Dieleman et al (2018) stated that present-day support can be characterised differently by individuals, in terms of relational support (love and affection) or competence support (planning and structuring). If this is the case, support from a significant other is not something that can be fully assessed using a predetermined, rigid measure such as MSPSS, as it does not allow the respondent to clarify the importance and type of support in relation to their life (Cozby & Bates, 2012; Hyman, Lamb & Bulmer, 2006). Therefore, this indicates that future studies could develop this line of study by investigating the perception of available support alongside the purpose of the support, in order to provide a comprehensive understanding its influence.

Multiple family process frameworks emphasize that family support can encourage parental adjustment and coping with stressors (Jones & Passey, 2005; Segrin & Flora, 2011; Weiss et al., 2013; Weiss, Wingsiong & Lunsky, 2014).

Research has shown that perceived family support can act as a resource to aid parental hardiness when coping with their child's diagnosis (Weiss et al., 2013). The current study found that PCASD reported a significantly lower perception of familial support compared to parents of TD children. Taken together, this could indicate that PCASD adjust to their child's diagnosis better when they consider their family as a support system, though when compared to a comparison group they did not perceive their family to be as great a resource. What is not fully understood is why PCASD perceived their family as less of a support than parents of TD children. Hence further research will be needed to explore this. However, it is proposed that until then, professionals should appraise the family hardiness of PCASD and identify positive elements to promote family resilience, as this could shape interventions used to strengthen parental and familial well-being when caring for a child with ASD (Kiami & Goodgold, 2017; Weiss et al., 2013; Weiss, Wingsiong & Lunsky, 2014).

The last part of this hypothesis, focusing on access to services, showed significant differences between PCASD and PCGC when compared to parents raising a TD child. To our knowledge, this is the first study to look at access to services as an influential support resource for parental groups. In the current study, both PCGC and PCASD reported perceiving significantly lower support from services than the comparison, though PCGC perceived slightly lower support from accessing services than PCASD. This could be explained in terms of the support service resources, as services such as Cafcass, preschools and medical facilities are readily available for parents raising a typically developing child (World Health Organisation, 2012), yet for parents of children with additional needs, access is more obtainable for certain cohorts of children with a specific diagnosis, meaning that some children and their parents are unable to access any service (Cantan & Bolger, 2017). Within this

research, PCGC comprised parents of children with a variety of different disabilities and as such, it is possible that a portion of these parents were included in the beforementioned percentage of people who are unable to access any service.

In such case, a thought-provoking finding is that PCASD did not report much higher scores than PCGC when compared to the comparison, yet in the last few decades the diagnoses of ASD have become more frequent and prevalent, thus arguing that many services should be adept in providing support for parents raising a child with ASD (Neggers, 2014). Results from the current study suggested that this may not be occurring, as PCASD reported significantly lower perceived support from services than the comparison. This indicates that there are still considerable challenges within support services that need to be addressed in order to successfully meet the needs of parents raising a child with either a disability or ASD. Hence, to support parents of children with a disability and ASD and protect their well-being, multiagency working needs to occur and establish equal access to services that is available for all parents, independent of their child's diagnosis (Cadwgan & Goodwin, 2018).

Hope

Investigation into hypothesis four revealed that PCASD and PCGC reported significantly lower levels of hope than parents of TD children. Whilst an understudied area of the literature, this finding is one that is supported by other research, illustrating that raising a child with a disability can influence the construct of hope in parental functioning (Cless et al., 2018; Ogston et al., 2011). Ogston et al (2011) found that PCASD reported the lowest levels of hope when compared to parents of children with Down Syndrome (DS). As previously discussed, this could be related to

the DS “advantage”, as the aetiology-related behaviour of DS children can lessen the stress of their parents when compared to parents of children with other intellectual disabilities (Mitchell, Hauser-Cram & Crossman, 2015). Additionally, PCASD may report lower hope scores than other disabilities due to their diagnosis; as previous research has stated that the understanding of ASD has been vague, both in society and professionally (Hoefman et al., 2014; King et al., 2006; Ogston et al., 2011). Yet, within the current study PCGC, which included diagnoses of DS, reported lower levels of hope than PCASD and a significantly lower amount when compared to the comparison. This contrasting finding may highlight a success of the decades-long effort of researchers, parents and practitioners who have propelled the investigation into ASD to shape practice and force society to better recognise ASD (Nordahl-Hansen, Hart & Øien, 2018).

Additionally, there were significantly lower pathway hope scores from PCGC and interestingly, significantly lower agency hope reported by PCGC and PCASD than the comparison. These findings support those of other research that have emphasised the impact of hope on parental wellbeing (Cless et al., 2018; Illum et al., 2018; King et al., 2006; Ogston et al., 2011; Reif et al., 2017; Schwartz & Hadar, 2007; Snyder, 2002). This study revealed lower levels of agency and pathway hope in parents of children with varying diagnoses when compared to the comparison. This is important to note, as agency and pathway relate to one’s ability to plan and achieve goals (Snyder, 2002), and when this function is significantly lower than normal, it can impact multiple areas of psychological wellbeing (Cless et al., 2018; Ogston et al., 2011). Therefore, suggesting that it may be helpful for professionals to use hope as a resource when supporting parents of children with disabilities and ASD, as it is a motivating and influential construct (Snyder, 2002) and as such,

intervention that prompts parents to foster hope could increase positive outcomes for both themselves and their children (Cless et al., 2018).

Predictor Variables

The final goal of this study was to investigate the difference in importance of factors associated with parental stress, and from this, there were three statistically significant predictors found. The first factor, and the strongest predictor of increased stress levels was lower levels of PSOC. It is worth noting that these findings also found a negative correlation between stress and PSOC, suggesting that those parents who had low levels of perceived parenting competence were more likely to report high levels of stress. This compliments prior research such as that of Ozturk et al (2014), who revealed a relationship between self-perceptions of the parenting role and anxiety. Taken together, these results indicated that parental well-being is associated with how parents perceive their ability to adapt to the nurturing role and support their child's development (Katkic et al., 2017; Ozturk et al., 2014). It suggests that the more satisfied parents feel with their caregiving knowledge and practices, the less they report feelings of stress. Thus, this study has practical implications as these findings argue that the diversity between parental style and experience needs to be considered when implementing intervention programmes to support parents of children with any additional needs.

The results also found negative correlations suggesting that raising a child with a disability, low levels of support, and low levels of hope were all related to high levels of stress. Further analysis illustrated that parental type was another significant predictor of stress in parents. Although these results contrast some research (Katkic et al., 2017), overall, they fall in line with many prior studies in this area, implying that

there is an important relationship between raising a child with additional needs and higher levels of stress (Bourke-Taylor et al., 2013; Estes et al., 2013; Feizi et al., 2014; Padden & James, 2017; Yamaoka et al., 2015). Given the unexpected challenges that occur when raising a child with a disability or ASD (Bourke-Taylor et al., 2013; Cadwgan & Goodwin, 2018; Estes et al., 2013; Feizi et al., 2014; Green, 2007; Hartley & Shultz, 2015; Pelchat & Lefebvre, 2003), it is understandable that this can present parents with additional and stressful difficulties. As previous results in this study also revealed differences between the type of child disability on parental stress, together these highlight the need to consider the diagnosis in further research and in interventions that are aimed at reducing parental stress.

Furthermore, it is noteworthy that of all the components of support, only familial support was found to be a significant predictor within this research. Higher levels of perceived familial support significantly predicted lower levels of stress in parents. This adds to the literature, as it argues that to fully understand social support, it is necessary to provide individuals with a way to explain the different attributes of support (Dieleman et al., 2018; Hartley & Shultz, 2015). The current study did this by investigating social support from three perspectives and accordingly revealed important differences between them. Thus, as the only significant predictor of stress in terms of support was familial, it could be assumed that there is a specific vulnerability for increased parental stress if familial support is perceived as absent. This lays foundation for future research in this area, as knowledge into the different attributes and sources of support for PCASD or other disabilities will allow professionals to promote positive adjustment behaviours for parents with limited support systems.

Other predictors that were included in the regression were hope subscales “agency” and “pathway” and support subscales “significant other” and “access to services”, though these were not significantly associated with stress. However, intriguingly, the initial data implied that limited access to services predicted higher stress, though once parental type was added to the regression, this relationship altered and suggested that increased access to services predicted higher stress. This indicates that these variables intertwined with one another, as there were changes in stress outcomes when variables were added or omitted, though how these variables interact is not completely clear. Clear delineation of the support services accessed by parents, such as the ease of gaining service support and the time provided by professionals, will provide insightful knowledge into this complex nature of this relationship; an important consideration for future research.

Additionally, these findings contrast prior research, as higher levels of hope have been found to reduce levels of stress in parents raising a child with a disability or ASD (Cless et al., 2018; Ogston et al., 2011), and higher perceived support from a significant other has also been related to lower reported stress in parents (Belsky, 1984; Findler et al., 2016). In the current study, the trend indicated that lower levels of hope in both subscales related to higher levels of reported stress, and higher perceived support from a significant other related to higher reported stress, even if this was not found at a significant level. However, this reported significance level should not cause these results to be disregarded, as a non-significant finding does not denote that there were no differences between the groups and can sometimes simply reflect variation in the group mean (Gelman & Stern, 2006). It may be that the quantitative nature of this research was too simplistic to study these variables; if the predetermined answer choices were unclear and inaccurate this could have limited

the responses of parents (Cozby & Bates, 2012; Hyman et al., 2006). Regardless, the trend found in the current study indicated some interaction between access to services, support from a significant other, hope and stress, and the inclusion of these variables in research sheds new light onto the area by exploring the benefits of the caregiving experience and the importance of external resources. Hence, they need to be studied in further detail to form a comprehensive understanding of their impact on the population.

Limitations and Future Direction

There are a few factors that need to be considered when interpreting the results of the current study. Firstly, the cross-sectional design of this study prevented the possibility of making any causal inferences. Thus, without acquiring prior baseline data it is not possible to report whether the differences between group stress levels were a direct result of raising a child with a disability or ASD, or whether higher levels of stress were reported due to the influence of confounding variables. To expand, stress is a dynamic construct and extraneous life-events and stressors, such as bereavement, job loss, divorce etc. are all individual life differences that can impact feelings of stress and coping (Padden & James, 2017; Segerstrom & O'Connor, 2012). Further, people experience stress differently, as it is influenced by their personality, temperament and their life stage (Segerstrom & O'Connor, 2012). Consequently, there is some variability in the literature regarding the outcomes of parents raising a child with a disability or ASD, and though much of this research outlines the negative impact associated with these caregiving experiences (Feizi et al., 2014; Green, 2007; Hartley & Shultz, 2015; Yamaoka et al., 2015), there is also research arguing that after an adjustment period, these parents report similar outcomes to those raising a TD child (Cless et al., 2018; Green, 2007; Katkic et al.,

2017; Ogston et al., 2011). Therefore, the current research encourages future studies to implement longitudinal methods of investigation, to understand the nature of stress over time and gain valuable insight into the variation both between and within parents raising a child with additional needs, which will have numerous implications for family-wide support.

The second limitation of this work concerns the sample of the study. There is research that has explored the differences between mothers and fathers raising a child with ASD, outlining distinctions between them and how they are best supported to protect their wellbeing (Hartley & Shultz, 2015). However, despite intention, the current study was not able to investigate the differences between mothers and fathers raising a child with additional needs, as the sample size was not large enough. This is also a criticism of many previous investigations as fathers are less researched in this area than mothers (Cless et al., 2018; Findler et al., 2016; Katkic et al., 2017; Yamaoka et al., 2015). It is possible that cultural and structural biases are still largely influential, causing fathers to perceive their main role as the family breadwinner and so do not actively involve themselves with research issues (Yogman & Garfield, 2016). To control for this, further studies need to seek out male participants, to ensure that they are equally represented in research and gain a better understanding of how they are affected, to inform intervention strategies of how they can best support the family as a whole.

Additionally, some research suggests that some parents of children with ASD tend to display elements of the broader autism phenotype (BAP) (Ingersoll & Wainer, 2014; Landry & Chouinard, 2016; Maxwell, Parish-Morris, Hsin, Bush & Schultz, 2013; Rubenstein & Chawla, 2018). BAP is a collection of milder autistic characteristics that are suggested to be more common in families of individuals

diagnosed with ASD (Rubenstein & Chawla, 2018). The current study did not investigate this construct in PCASD which may have impacted the results that were obtained. Research suggests that of parents raising a child with ASD, the presence of BAP is more commonly found in a single parent and this may influence their parental behaviours and generate additional stress for both themselves and their partner (Maxwell et al., 2013; Sasson, Lam, Parlier, Daniels & Piven, 2013). Further, it is argued that the presence of BAP characteristics in parents is moderately positively associated with their child's autism symptomology (Maxwell et al., 2013). Therefore, future research needs to explore ASD and BAP separately if it is to investigate the impact of raising a child with ASD comprehensively. Such knowledge could inform professionals of how they can best support families of children with ASD.

Conclusion

In accordance with the hypotheses, these results found that parents of children with ASD reported the highest level of stress, though both PCASD and PCGC reported significantly higher stress, lower perceived parental competence, social support and hope than parents of typically developing children. Furthermore, by exploring a wide range of variables in relation to raising a child with additional needs, it was revealed that PSOC was the strongest predictor of parental stress. This has implications for the way intervention services implement programmes to support parents raising a child with a disability or ASD, as it highlights that the relationship between stress and raising a child with a disability is not predetermined and can be shaped by multiple other factors that need to be acknowledged. These findings suggest that it is not enough for professionals to inform and consult with parents, as they need to assist them through training, teaching and engagement to

encourage confidence in their parenting practices. This should also be tailored to each family's needs, as these results highlight differences in stress when comparing PCASD and PCGC, supporting research that indicates variability in the outcomes of parents raising a child with a disability relating to diagnosis. This in turn will support the mental well-being of all parents raising a child with additional needs and promote positive adjustment.

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Appendices

Appendix A: Ethics and Amendment Forms.

Staff / Office Use Only
DOPEC NUMBER: *Click here to enter text.*
Umbrella project DOPEC number (staff) *Click here to enter text.*

APPLICANT SURNAME Keane

APPLICANT:	UG ☐	PGT ☒	PGR ☐	Staff ☐
REVIEW PROCESS:	Accelerated ☐	Full ☒		
APPLICATION STATUS:	New application ☒	Major amendment ☐	Resubmission ☐	
APPLICATION FOR:	Dissertation ☒	Teaching ☐	Research & publication ☐	
ATTTENDENCE AT HEALTH & SAFETY BRIEFING:	Yes ☒	No ☐	N/A ☐	
INCLUSION OF RISK ASSESSMENT FORM:	Yes ☐	No ☐	N/A ☒	

NOTES ON THE ROLE AND FUNCTION OF THE DEPARTMENT OF PSYCHOLOGY ETHICS COMMITTEE.

- *All decisions of the committee are based on the application form and reviewers comments ONLY. Forms should be as detailed and clear as possible. Verbal discussions are not considered as part of the application or review process.*
- *The review process strictly adheres to the University of Chester Research Governance Handbook and the BPS Code of Ethics.*
- *The decision of the committee is final. If you are a UG, PGT or PGR student you should discuss the decision of the committee with your supervisor. If you are a member of staff you may contact the chair of the committee for further clarification.*

Before completing the form researchers are expected to familiarise themselves with the regulatory codes and codes of conduct and ethics relevant to their areas of research, including those of relevant professional organisations and ensure that research which they propose is designed to comply with such codes.
Department of Psychology Ethical Approval for Research: Procedural Guidelines.
University of Chester Research Governance Handbook
http://ganymede2.chester.ac.uk/view.php?title_id=522471
BPS Code of Ethics
http://www.bps.org.uk/system/files/Public%20files/bps_code_of_ethics_2009.pdf
BPS Code of Human Research Ethics
http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf
BPS Guidelines for Internet-mediated Research
http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf
BPS Research Guidelines and Policy Documents
http://www.bps.org.uk/publications/policy-and-guidelines/research-guidelines-policy-documents/research-guidelines-poli

Any queries email: n.davies@chester.ac.uk or psychology_ethics@chester.ac.uk

CHECK LIST.

Please complete the form below indicating attached materials. Prior to submission supervisors must confirm that they have reviewed the application by completing the supervisors column.

Notes: Students to indicate where information is found, supervisor to confirm by ticking green column	Supervisor confirmation	Information sheet	Letter	Email	Email info. page	Consent Form	PowerPoint	N/A
Brief details about the purpose of the study	☒	☒	☐	☐	☐	☒	☐	☐
Contact details for further information	☒	☒	☐	☐	☐	☐	☐	☐
Explanation of how and why participant has been chosen	☒	☒	☐	☐	☐	☐	☐	☐
Notification that materials/interviews are not diagnostic tools/therapy or used for staff review/development purposes	☒	☒	☐	☐	☐	☐	☐	☐
Explanation participation is voluntary	☒	☒	☐	☐	☐	☒	☐	☐
Details of any incentives or compensation	☒	☐	☐	☐	☐	☐	☐	☒
Details of how consent will be obtained	☒	☐	☐	☐	☐	☒	☐	☐
If research is observational, consent to being observed	☒	☐	☐	☐	☐	☐	☐	☒
Details of procedure so participants are informed about what to expect	☒	☒	☐	☐	☐	☐	☐	☐
Details of time commitments expected	☒	☒	☐	☐	☐	☐	☐	☐
Details of any stimuli used	☒	☐	☐	☐	☐	☐	☐	☒
Explanation of right to withdraw and right to withdraw procedure	☒	☒	☐	☐	☐	☒	☐	☐
Option for omitting questions participant does not wish to answer	☒	☒	☐	☐	☐	☐	☐	☐
Procedure regarding partially completed questionnaires or interviews	☒	☒	☐	☐	☐	☐	☐	☐
With interviews, information regarding time limit for withdrawal	☒	☐	☐	☐	☐	☐	☐	☒
Details of any advantages and benefits of taking part	☒	☒	☐	☐	☐	☐	☐	☐
Details of any disadvantages and risks of taking part	☒	☒	☐	☐	☐	☐	☐	☐
Information that data will be treated with full confidentiality and that, if published, those data will not be identifiable as theirs	☒	☒	☐	☐	☐	☒	☐	☐
Debriefing details	☒	☒	☐	☐	☐	☐	☐	☐
Dissemination information	☒	☒	☐	☐	☐	☐	☐	☐
Further information (relevant literature; support networks etc)	☒	☒	☐	☐	☐	☐	☐	☐

Supervisor Signature: L.P. O'Neill ***Date :08/02/2018***

University of Chester

DEPARTMENT OF PSYCHOLOGY APPLICATION TO DEPARTMENTAL ETHICS COMMITTEE

WHEN COMPLETING THE FORM PLEASE REFER TO THE DOP ETHICS PROCEDURAL GUIDELINES HANDBOOK.
UG AND PGT STUDENTS CAN ACCESS A COPY ON THEIR RELEVANT MOODLE PAGE.
PGR AND STAFF SHOULD CONTACT n.davies@chester.ac.uk or psychology_ethics@chester.ac.uk

1. Working title of the study

Notes: The title should be a single sentence

Parental wellbeing: Caring for a child with a disability.

2. Applicant name and contact details

Notes: The primary applicant is the name of the person who has overall responsibility for the study. Include their appointment or position held and their qualifications. For studies where students and/or research assistants will undertake the research, the primary applicant is the student (UG, PGT, PGR) and supervisor is the co-applicant.

Kerry Keane, 1304170@chester.ac.uk

3. Co-applicants

Notes: List the names of all researchers involved in the study. Include their appointment or position held and their qualifications

Linda O'Neill, PhD
Senior Lecturer in Psychology
Department of Psychology
University of Chester

4. Start and end dates of the study

Notes: The title should be a single sentence

Ethics form to be submitted before 9th February 2018. Then the method and a comprehensive literature review will be written while waiting for ethical approval- and this will continue once ethical approval has been granted and data collection starts. If ethics is approved, the start date for data collection will be February 2018. It is expected that the data collection will be carried out up until July 2018. After the data has been collected, data analysis will immediately start and the study should be completed by September 2018.

5. Is this project subject to external funding?

Notes: Please provide details of the funding body, grant application and PI.

This project is not subject to external funding.

6. Briefly describe the purpose and rational of the research

Notes: (Maximum 300 words). In writing the rationale make sure that the research proposed is grounded in relevant literature, and the hypotheses emerge from recent research and are logically structured.
If this application is for a PGR/Staff funded project please attach any detailed research proposals as appropriate.

Whilst there are typical challenges that occur whilst raising a child, having a child with developmental or psychological problems can create extra difficulties for parents who take care of them (Feizi, Najmi, Salesi, Chorami & Hoyeidafar, 2014). When children are diagnosed with long-term limitative conditions, this can lead to increased stress levels not only for that child but also for their family (Feizi et al, 2014). Caring for a child with special needs is an unexpected experience for parents and this can result in physical problems, mental health problems and financial burdens (Bourke-Taylor, Pallant, Law and Howie, 2013; Estes et al, 2013). For instance, Yamaoka et al (2016) studied the relationship between raising a child with disabilities and maternal psychological distress. They found that even for mothers who received consistent support from their significant other, there was a significant positive association between raising a child with disabilities and psychological distress.

Previous studies focusing on parents who have children with disabilities have looked at either mental health or emotional status (Estes et al, 2013, Feizi et al, 2014). Therefore, the current study will aim to assess the relationship between raising a child with disabilities and the mental health of parents compared to mothers of children without disabilities. Furthermore, the current study intends to look at the role of support services on parental mental well-being and whether they mediate the impact that raising a child with disabilities has on psychological wellbeing. Lastly, this study aims to look at the levels of hope in parents who have a child with disabilities and parents who have typically developing children to investigate whether this has an ameliorative effect on parental well-being.

7a. Describe the methods and procedures of the study

Notes: (Maximum 500 words) Attach any relevant material (questionnaires, supporting information etc.) as appendices and summarise them briefly here (e.g. Cognitive Failures Questionnaire: a standardised self-report measure on the frequency of everyday cognitive slips). Do not merely list the names of measures and/or their acronyms. Include information about any interventions, interview schedules, duration, order and frequency of assessments. It should be clear exactly what will happen to participants. If this is a media based study describe and list materials include links and sampling procedure.

Data will be collected online via an online questionnaire (see appendix A). This will contain a demographics section; questions regarding sex and age etc, the Perceived Stress Scale [PSS] (Cohen, Kamarck & Mermelstein, 1983), the Parenting Sense of Competence Scale [PSOS] (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989) and The Adult Dispositional Hope Scale [AHS] (Snyder et al, 1991) and the Multidimensional Scale of Perceived Social Support [MSPSS] (Zimet, 1988).

In particular the PSS was chosen as a method to assess parental stress, as it has consistently reported high levels of validity and reliability across populations (Wu & Amtmann, 2013). The PSOS will be utilised as it has shown great generalisability across samples and has been used not only in research focusing on maternal sense of competence (Karp, Lutenbacher & Wallston, 2015) but also to study paternal sense of competence (Ohan, Leung & Johnston, 2000); something that will benefit the current research. The PSOS measures perceived competence of parents on two dimensions: satisfaction and efficacy (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989).

The AHS will be included within this study and participants will be asked to relate these questions to parenting a child with disabilities, as previous research has tended to focus on the negative issues that can arise when caring for a child with a disability, including illness, pressure and

maladjustment (Kandel & Merrick, 2007). Therefore, the current study would like to build upon this and highlight the possibility of positive functioning that may also occur when caring for a child with a disability.

Finally, the MSPSS will be used to assess the relationship between perceptions of social support and wellbeing. The MSPSS is a 12-item scale that usually assesses relationships with family, friends and a significant other. As an assessment tool, this scale has been shown to be a solid research instrument (Stewart, Umar, Tomenson & Creed, 2014; Zimet, Dahlem, Zimet & Farley, 1988). For the purpose of this study, this scale will still address three subscales of support, though these will instead be 'family', 'significant other' and 'access to services'. So, though two subscales will remain the same, questions relating to 'access to services' will replace the questions relating to 'friends' in this scale (see appendix A), as this is the factor my study aims to focus on. Additionally, access to services as opposed to support from friends has been reported by parents who have a child with disabilities, as a more beneficial resource to them (Beresford, Rabiee & Sloper, 2007). This will be a simple change, for instance one of the typical MSPSS questions relating to 'friends' reads "I have friends with whom I can share my joys and sorrows". The revised question here will actually read "I can easily access a support service that I am able to share my feelings with". Thus, the question overall will be examining similar feelings though it will be worded differently to investigate an alternative subscale.

This study will be a between-subjects design. The results will first be analysed using descriptive statistics and further analyses will include correlation analysis, hierarchical multiple regression and mediation analysis using PROCESS (Hayes, 2013).

7b. Provide details of your contingency plan

Notes: Please briefly describe your contingency plan. (100 words)

A contingency plan has been discussed with supervisor. For instance, as supervisor has much experience in this area, we have discussed the possibility of investigating sibling wellbeing, in place of parental wellbeing, if it is not possible to get enough participants for the original idea to investigate the wellbeing of parents who have children with disabilities. Supervisor has sufficient existing data available for this.

8. Provide details of the previous experience of the procedures by the person conducting the study.

Notes: Say who will be undertaking the procedures involved and what training and/or experience they have. If supervision is necessary, indicate who will provide it.

Supervisor has much experience in this area and in statistical analysis, and researcher also has experience in statistical analysis.

9. Describe the ethical issues raised by this study and discuss the measures taken to address them.

Notes: Describe any discomfort or inconvenience that participants may experience. Include information about procedures that for some people could be physically stressful or might impact on the safety of participants, e.g. interviews, probing questions, noise levels, visual stimuli, equipment; or that for some people could be psychologically stressful, e.g. mood induction procedures, tasks with high failure rate, please include your distress protocol. Discuss any issues of anonymity and confidentiality as they relate to your study, refer to ethics handbook and guidance notes at the end of the form. If animal based include ethical issues relating to observation.

Participants may be put under some psychological distress as they are asked about their children and some of these participants will have a child with a disability. This may cause some emotional discomfort or distress as they are recalling information about their lives, related to their children, that they may feel is a sensitive issue. Therefore, the participants will be informed prior to the start

of the study that they will be asked about the wellbeing of their child and themselves and that if this may cause any distress to them, they should discontinue with the study. They will also be informed prior to starting that if they do start the study, they will be able to stop at any time if they feel unable to complete it, but they will be advised to continue clicking the 'next' button at the bottom of the page until they reach the debriefing sheet which will contain helpline numbers. Helpline numbers will be given to the participant, if they feel they would like to talk to someone. In addition, it will be emphasised that none of the survey should be considered as a diagnostic tool for the participant. On completion of the study, in the debrief section, participants will be informed again of the nature of the research, and additional helpline numbers will be provided in case of any distress caused on completion of the study or at the debriefing stage.

Participants will also be told not to complete the questionnaire with any identifying information, thus they will not be able to be identified at any time during or after completion. Once the data has been completed, it will remain safely on a singular USB stick, which will reside within a locked draw unless in use. Additionally, no completed questionnaires will be attached to the dissertation, only the data analysis will be shown.

Participants will be informed that they will be able to withdraw from the study at any time up until the completion and submission of their data, this is because their data will be anonymous on submission and so will not be identifiable to remove it. They will be given an option to discontinue at each stage throughout the study as they will be told in the information sheet prior to starting that if they feel they are unable to continue, they should not answer any more questions and proceed to the end of the questionnaire to the debrief sheet which will contain any helpline numbers they feel they might need.

10.Describe the participants of the study.

Notes: Describe the groups of participants that will be recruited and the principal eligibility criteria and ineligibility criteria. Make clear how many participants you plan to recruit into the study in total.

Participants will be invited to take part if they have children, if they themselves are aged over 18. The under-18 exclusion is because teen parents, even of typically developing children, have been shown to have additional problems when caring for a child (Garrison & Felice, 2009), that may bias the results of this data. There will be no age limit for the age of their child. It is proposed that half of the participants will be parents of typically developing children and half of the participants will be parents who have at least one child with a diagnosed disability will be a requirement. The study will be advertised to both males and females; mothers and fathers. It is estimated that there will be a range of socioeconomic backgrounds among the individuals recruited.

11. Describe the participant recruitment procedures for the study.

Notes: Gives details of how potential participants will be identified or recruited, please list any social media platforms that you will use and the message. Include all other advertising materials (posters, emails, letters, verbal script etc.) as appendices and refer to them as appropriate. Describe any screening examinations. If it serves to explain the procedures better, include as an appendix a flow chart and refer to it.

Participants will be recruited using an opportunity sample. To recruit participants online support group sites will be utilised, such as those found on Facebook. It is estimated that the sample will contain mostly females, as males are less likely to seek out help and support (Pelchat, Lefebvre & Perreault, 2003). A short message (see Appendix B) will be posted on to support sites found on Facebook, to recruit participants, asking them to take part in the study that will be linked to them. For support groups found online only, and not on social media site such as Facebook, a message will be posted on discussion boards (see appendix C) asking for participants who are willing to take part. They will be asked to email the attached email address and if so will receive an email back (see appendix D) with some information and a link to the questionnaire.

12. Describe the procedures to obtain informed consent

*Notes: Describe when consent will be obtained. If consent is from **adult participants**, give details of who will take consent and how it will be done. If you plan to seek informed consent from **vulnerable groups** (e.g. people with learning difficulties, victims of crime), say how you will ensure that consent is voluntary and fully informed.*
*If you are recruiting **children or young adults** (aged under 18 years) specify the age-range of participants and describe the arrangements for seeking informed consent from a person with parental responsibility. If you intend to provide children under 16 with information about the study and seek agreement, outline how this process will vary according to their age and level of understanding.*
How long will you allow potential participants to decide whether or not to take part?
What arrangements have been made for people who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?
If you are not obtaining consent, explain why not.

Informed consent will be gained from participants before they start the questionnaire. They will read an information page that describes the study and informs them of what they should do (see appendix E). This information page will inform them to only take part if they are able to fully understand the information that they have read. They will also be told that if they choose to continue with the study, this will be taken as consent to take part in the study. There will be no time limit on the whole study and they will have as much time as they wish to decide whether they want to take part. They will also be informed that they are able to stop the study at any time and will be given chances to discontinue with the study at any stage of the questionnaire. For example, the information sheet read by participants prior to starting the questionnaire will inform them that if they do not wish to continue, to refrain from answering any further questions and simply press the 'next' button at the bottom of the page until they reach the debrief sheet.

13. Will consent be written?

Yes ☐ *No* ☒

*Notes: If **yes**, include a consent form as an appendix. If **no**, describe and justify an alternative procedure (verbal, electronic etc.) in the space below.*
Guidance on how to draft Participant Information sheet and Consent form can be found on PS6001 Moodle space and in the Handbook.

As this will be an online study, a consent form will be provided to the participant as a singular page. Participants' will be told at the end of this consent form that if they click next and continue with the study, that this will be taken as consent.

14. Describe the information given to participants. Indicate if and why any information on procedures or purpose of the study will be withheld.

Notes: Include an Information Sheet that sets out the purpose of the study and what will be required of the participant as appendices and refer to it as appropriate. If any information is to be withheld, justify this decision. More than one Information Sheet may be necessary.

Participants will be told the purpose of the study on the information sheet. No information will be withheld (see appendix E).

15. Indicate if any personally identifiable information is to be made available beyond the research team. (eg: a report to an organisation)

Notes: If so, indicate to whom and describe how confidentiality and anonymity will be maintained at all stages.

There will be no personally identifiable information made available beyond the research team. The study will be completely anonymous.

16. Describe any payments, expenses or other benefits and inducements offered to participants.

Notes: Give details. If it is monetary say how much, how it will be paid and on what basis is the amount determined. Indicate RPS credits.

There will be no payments, expenses or inducements offered to participants.

17. Describe the information about the investigation given to participants at the end of the study.

Notes: Give details of debriefings, ways of alleviating any distress that might be caused by the study and ways of dealing with any clinical problem that may arise relating to the focus of the study.

On completion of the questionnaire participants will be directed to a debriefing form (see appendix F). This will thank the participants for taking part in the research and provide a brief explanation of the purpose of the study and what it intends to find. It will also contain helpline numbers that participants will be advised to contact if they feel that their participation in the study has caused them distress in any way. Additionally, it will provide information on how to find out any of the concluding results if they so wish.

18. Describe data security arrangements for during and after the study.

Notes: Digital data stored on a computer requires compliance with the Data Protection Act; indicate if you have discussed this with your supervisor and describe any special circumstances that have been identified from that discussion. Say who will have access to participants' personal data and for how long personal data will be stored or accessed after the study has ended.

All data will be collected online and research materials will be stored on a single encrypted password-protected USB stick that will remain in a locked drawer unless in use. Participants will take part in the research anonymously, so there will be no identifying information in any of the data collected. Once the degree has been awarded and the materials are no longer needed for use, all data collected will be completely erased. However, if the paper is accepted for publication then all materials will be kept for a further five years before they are erased.

SIGNATURES OF THE RESEARCH TEAM

Notes: The primary applicant and all co-applicants must sign and date the form. Scanned or electronic signatures are acceptable.

K. Keane
06/02/2018

L.P. O'Neill
08/02/18

ETHICS COMMITTEE DATE 22/02/2018

☐ ACCEPTABLE

You may now commence data collection subject to approval from any relevant external agencies.

CHAIRS COMMENTS

☒ Read and review all reviewers comments

The social media message states that only biological parents should take part, as there is no genetic biological like being looked at, what if IVF was involved or the child is adopted?

DATA COLLECTION IS NOT PERMISSABLE UNDER THE FOLLOWING 3 CONDITIONS. Please address the issues indicated.

☒ ACCEPTABLE SUBJECT TO SUBMISSION OF AMENDMENT FORM

UG and PG students should discuss any recommendations with their supervisors.

☐ ACCEPTABLE SUBJECT TO CONDITIONS OF CHAIR

Resubmit application for full review after addressing the issues described, ensuring you have indicated on the front page of the form that this is a resubmission.

☐ REVISE AND RESUBMIT

Resubmit application for full review ensuring you have indicated on the front page of the form that this is a resubmission

SIGNATURE:

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Appendix A: Questions to make up questionnaire.

(Note: These are only the questions that will be used within the questionnaire for this study- when the questionnaire has been created, all of the questions will have the same format)

Are you a biological mother? Yes/No
Are you a biological father? Yes/No
What is your age?
Are you married? Yes/No
Are you in a relationship? Yes/No
Are you employed full-time? Yes/No
Are you employed part-time? Yes/No
Are you unemployed? Yes/No
How many children do you have?
Does at least one of your children have a disability?
If yes:
What is the diagnosis of your child?
What is the severity of your child's diagnosis? Profound- severe- moderate- mild
How many children without disabilities do you have? []
How many other children with disabilities do you have? []
Is this the same disability as your child mentioned above? Yes/No

In the last month, how often have you felt nervous and "stressed"?	Never Often 1	2	3	4	Very 5
In the last month, how often have you dealt successfully with irritating life hassles?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt confident about your ability to handle your personal problems?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that things were going your way?	Never Often 1	2	3	4	Very 5
In the last month, how often have you found that you could not cope with all the things you had to do?	Never Often 1	2	3	4	Very 5
In the last month, how often have you been able to control irritations in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were unable to control the important things in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were on top of things?	Never Often 1	2	3	4	Very 5
In the last month, how often have you been upset because of something that happened unexpectedly?	Never Often 1	2	3	4	Very 5

Appendix A: Questions to make up questionnaire.

(Note: These are only the questions that will be used within the questionnaire for this study- when the questionnaire has been created, all of the questions will have the same format)

Are you a biological mother? Yes/No
Are you a biological father? Yes/No
What is your age?
Are you married? Yes/No
Are you in a relationship? Yes/No
Are you employed full-time? Yes/No
Are you employed part-time? Yes/No
Are you unemployed? Yes/No
How many children do you have?
Does at least one of your children have a disability?
If yes:
What is the diagnosis of your child?
What is the severity of your child's diagnosis? Profound- severe- moderate- mild
How many children without disabilities do you have? []
How many other children with disabilities do you have? []
Is this the same disability as your child mentioned above? Yes/No

In the last month, how often have you felt nervous and "stressed"?	Never Often 1	2	3	4	Very 5
In the last month, how often have you dealt successfully with irritating life hassles?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt confident about your ability to handle your personal problems?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that things were going your way?	Never Often 1	2	3	4	Very 5
In the last month, how often have you found that you could not cope with all the things you had to do?	Never Often 1	2	3	4	Very 5
In the last month, how often have you been able to control irritations in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were unable to control the important things in your life?	Never Often 1	2	3	4	Very 5
In the last month, how often have you felt that you were on top of things?	Never Often 1	2	3	4	Very 5
In the last month, how often have you been upset because of something that happened unexpectedly?	Never Often 1	2	3	4	Very 5

	Definitely False							Definitely True
I can think of many ways to get out of a jam.	1	2	3	4	5	6	7	8
I energetically pursue my goals.	1	2	3	4	5	6	7	8
I feel tired most of the time.	1	2	3	4	5	6	7	8
There are lots of ways around any problem	1	2	3	4	5	6	7	8
I am easily downed in a argument.								
I can think of many ways to get the things in life that are important to me.	1	2	3	4	5	6	7	8
I worry about my health.	1	2	3	4	5	6	7	8
Even when others get discouraged, I know I can find a way to solve the problem.	1	2	3	4	5	6	7	8
My past experiences have prepared me well for my future.	1	2	3	4	5	6	7	8
I've been pretty successful in life.	1	2	3	4	5	6	7	8
I usually find myself worrying about something.	1	2	3	4	5	6	7	8
I meet the goals that I set for myself.	1	2	3	4	5	6	7	8

	Very strongly disagree						Very strongly agree
1. There is a special person that is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really try to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. I feel I receive sufficient and frequent help from the support services that are available to me.	1	2	3	4	5	6	7
7. I can count on support services to provide helpful information and resources when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I can easily access a support service that I am able to share my feelings with.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. There is always a support service accessible to me where I can talk about my problems if I need to.	1	2	3	4	5	6	7

Appendix B: Facebook Message.

For my Masters Dissertation Project, I am required to complete a piece of work related to a specific field of my choosing. Therefore, I hope to look at the mental wellbeing of parents who have children with disabilities. I also intend to look at the influence of hope and access to services and whether they effect parental mental wellbeing. I would appreciate it if you could take 20 minutes out of your day to complete this short questionnaire. All information collected is anonymous and confidential throughout the completion of the questionnaire and after submission. All biological parents are asked to take part in this questionnaire, both mothers and fathers who have children that have at least one disability and those with typically developing children. If you would like to take part please send me a message and I will forward you the link to the questionnaire. Thank you.

Appendix C: Discussion board Message.

Hello,
My name is Kerry and I am a Family and Child Psychology Masters student. For my Masters Dissertation Project, I am required to complete a piece of work related to a specific field of my choosing. Therefore, I hope to look at the mental wellbeing of parents who have children with disabilities. I also intend to look at the influence of hope and access to services and whether they effect parental mental wellbeing. If you would like to take part could you please respond to the following email address: and you will be directed to the necessary study page. All information collected is anonymous and confidential throughout the completion of the questionnaire and after submission. All biological parents are asked to take part in this questionnaire, both mothers and fathers who have children who have a disability and those with typically developing children. If you would like to take part please send me a message and I will forward you the link to the questionnaire. Thank you.

Appendix E: Information Sheet.

You are being invited to take part in a study that aims to look at the mental wellbeing of parents who have children with disabilities. In addition to this, the study will also look at the mediating role of hope and access to services on mental wellbeing. Anyone who is a parent is invited to take part; those who have children with a disability and those with typically developing children, as I am hoping to compare the mental wellbeing of parents with typically developing children against that of parents with children who have a disability. You may also enjoy learning about any results that are concluded from the study.

Please carefully read through the following information sheet before you decide whether you would like to take part in the study.

This study is made up of an online questionnaire that will take around twenty minutes to complete. It contains questions that will relate to stress levels, levels of hope, perceived parental competence and social support. For your own anonymity you are asked to ensure that you refrain from using any identifying information. The questions used are for research purposes only and should not be used in any way as a diagnostic tool. It is important that you answer all of the questions that are listed, though if you feel that you cannot continue you are able to withdraw from the study at any time by exiting the screen, though please be advised to keep clicking the 'next' button at the bottom of the page so that you can access the debrief sheet with helpline numbers if required. However, once you have submitted your completed questionnaire you will no longer be able to withdraw your information as it will all be completely anonymous and therefore will not be able to be located.

Please note that answers are not marked as correct or incorrect, you are only asked to answer these questions as honestly as possible as they relate to you. Once you have completed the study, you will be directed to debriefing form which will include additional helpline numbers that you are able to contact if you feel that any part of the study caused you any distress.

All of the information that is collected will be completely anonymous and will remain confidential at all stages of research. I would like to reiterate that participation is voluntary; it is solely your decision to take part in this study.

It is important to note that completion of the questionnaire signifies that you have given your consent to take part and allow your data to be analysed.

I would like to thank you for reading this information sheet and taking part in this study. All contact details, for any additional information you would like to know, can be found below.

Researcher: Kerry Keane- 1304170@chester.ac.uk
Supervisor: Dr Linda O'Neill- Loneill@chester.ac.uk Telephone: 01244 513193
Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Thank you for your time and for reading this information sheet.
Kerry Keane.

Appendix F: Debriefing details.

I would like to thank you for completing this questionnaire and taking part in the research being conducted. Again, I would like to reiterate that the questions used within this questionnaire are used for research purposes only and should not in any way be used as a diagnostic tool. Any information that is collected will be kept confidential and the concluding data will be published anonymously. If you are interested about the topic, or would like to know more about the research results, you are welcome to email any queries to the contact details that are listed below.

Researcher: Kerry Keane- 1304170@chester.ac.uk
Supervisor: Dr Linda O'Neill- Loneill@chester.ac.uk
Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ.

The main purpose of this study is to understand whether parenting a child with disabilities has a negative impact on parental mental wellbeing. This investigation also intends to look at the influence of hope and support, and whether these variables moderate the results.
There has been previous research conducted in this area that has provided guidance for the research hypothesis for the current study, those being:

- There will be decreased psychological wellbeing in parents of children with a disability than the control group.
- There will be increased levels of psychological wellbeing in parents who have frequent access to support than those who have more limited support.
- We are also trying to establish whether there is a difference in hope levels in parents who have children with disabilities and the control group.

If you feel that your participation in this research study has caused you any distress or harm, you are advised to speak to someone as soon as possible. There are helpline numbers provided below that you are able to contact:

The Parents Helpline: 0808 802 5544
Family Lives: 0808 800 2222
Contact a Family: www.cafamily.org.uk – Helpline number: 0808 808 3555
Disabled Parents Network: www.disabledparentsnetwork.org.uk – Helpline number: 0870 241 0450
Samaritans: jo@samaritans.org - Helpline number: 116 123 (UK).

Again, I would like to express my gratitude to you for taking part within this study. Thank you.

University of Chester

DEPARTMENT OF PSYCHOLOGY
ETHICS REVIEW FORM

When completing this form, please highlight the appropriate response to each question (e.g. underline, italicise, delete unwanted responses). Make any comments that you feel should be raised either next to each section or at the end in the general comments box.

Name of applicant: **KEANE, Kerry**

Project title: **Parental wellbeing: Caring for a child with a disability.**
Applicant status: PGT

1. **Has the applicant signed and dated the form?**
   a) Yes.

2. **What is the submission type?**
   a) First submission to this or any other committee? Yes

3. **Research Plan and Methodology (Qu 4, 6 & 7)**
   a) Are the timescales provided appropriate?
   Yes Comments:

   b) Are there contingency details?
   Yes Comments:

   c) Is the study well formulated in terms of drawing on the relevant literature and is it methodologically, analytically and scientifically sound?
   Yes Comments:

   d) Are appropriate debrief details provided?
   Yes Comments:

   e) Has the applicant provided appropriate details of where the research will take place?
   Yes Comments:

   f) Has the applicant provided appropriate details concerning data analysis?
   Yes Comments:

4. **Ethical Issues (Qu 9)**
   a) Is there consideration of how to minimise, manage and monitor issues of distress and harm, however minor?
   Yes Comments:

   b) Are appropriate details regarding the use and management of deception provided?
   Yes Comments:

c) Has the applicant provided appropriate details including regarding permission and appropriate health and safety information for conducting the study at the proposed location? Is the necessary documentation attached?
Yes Comments:

d) Has the applicant provided an appropriate overview of how they would manage participant distress?
Yes Comments:

5. Sample size, participants and recruitment (Qu 10 – 14)

a) Has the applicant provided appropriate details of the sample and how it will be identified?
Yes Comments:

b) If using social media for recruitment have details been provided on

a. Proposed sites
Facebook ☐
Twitter ☐
Instagram ☐
Other, please Specify
Comments:

b. Social media messages?
Facebook ☐
Twitter ☐
Instagram ☐
Other, please Specify
Comments:

c) Has the applicant provided appropriate details and attached the necessary documentation concerning their recruitment procedures? In particular, have they appropriately considered how to minimise, manage and monitor issues of distress and harm during recruitment?
Yes Comments:

d) Are there appropriate details on the information sheet regarding the following (if applicable):

- Purpose of the study Yes
- Explanation of why participant has been chosen Yes
- Details of materials/stimuli/qualitative topics Yes
- Notification that materials used in the study are not diagnostic tools/therapy Yes
- Notification that participation is voluntary Yes
- Incentives/Compensation Yes
- Informed consent Yes
- Procedure Yes
- Time commitment Yes
- Right to not answer questions Yes
- Withdrawal Yes
- How partially collected data will be used Yes
- Benefits and risks of participating Yes
- Anonymity Yes
- Confidentiality Yes
- Dissemination information Yes

6. Dissemination (Qu15)

a) Has the applicant provided appropriate details concerning research dissemination?

Yes Comments:

b) Are there appropriate details regarding any specific considerations about sharing the research?
Yes Comments:

7. Participant payments and inducements (Qu16)

a) Are there appropriate details regarding compensation arrangements?
Comments:

8. Debrief (Qu17)

a) Are appropriate debrief details provided?
Yes Comments:

b) Are there appropriate details about how participants will be debriefed should they decide to withdraw from an online study?
Yes Comments:

9. Data Security (Qu18)

a) Has the applicant provided appropriate details concerning data protection and storage?
Yes Comments:

b) Have security issues been properly considered?
Yes Comments:

c) Are there appropriate details regarding how privacy and confidentiality will be maintained during dissemination?
Yes Comments:

10. Forum-based projects: Not applicable, so answers left blank.

a) Is the content of the website openly accessible?
Yes / No Comments:

b) Has the applicant discussed what will happen with users who expressly state that they do not wish their responses to be used for research purposes?
Yes / No Comments:

c) Has the applicant explained how online data collected will be anonymized?
Yes / No Comments:

d) Has the applicant explained process of access, should the host website require posts to be posted through moderators
Yes / No Comments:

e) Has the applicant detailed how, where appropriate, they will ensure that age limits are met?
Yes / No Comments:

General comments: A very interesting study, with very sensitive content, but with all necessary safeguards in place.
Just an observation (not related to ethics) – recruitment is to be of fathers / mothers, but one of the questionnaires refers to mothers only in some questions. This may be worth some minor rephrasing.

Review status (please highlight one of the following):

Chair's action
~~Staff/PGR for full review~~
~~UG/PGT for full review~~
~~Work with external agencies~~
~~Work with vulnerable participants~~
~~Other issues/concerns~~

NAME: Astrid Schepman

ROLE: Reviewer 1

DATE: 9/2/18

University of Chester

DEPARTMENT OF PSYCHOLOGY
ETHICS REVIEW FORM

When completing this form, please highlight the appropriate response to each question (e.g. underline, italicise, delete unwanted responses). Make any comments that you feel should be raised either next to each section or at the end in the general comments box.

Name of applicant: Kerry Keane

Project title: Parental wellbeing: Caring for a child with a disability.

Applicant status: UG PGT PGR Staff

1. **Has the applicant signed and dated the form?**
   a) Yes / No → Return to applicant for signature before continuing with review process.

2. **What is the submission type?**
   a) First submission to this or any other committee? Yes / No

   b) Resubmission of a rejected application by this committee
      - Is there a summary of the requirements of the committee and is the original application attached? Yes / No→ Return to applicant for full details

   c) Revised submission intended to replace an application approved by this committee
      - Is the original application attached?: Yes / No→ Return to applicant for full details

   d) First submission to this committee; has been submitted to another committee.
      - Is the original application attached? Yes / No→ Return to applicant for full details

3. **Research Plan and Methodology (Qu 4, 6 & 7)**
   a) Are the timescales provided appropriate?
   Yes / No Comments:

   b) Are there contingency details?
   Yes / No Comments:

   c) Is the study well formulated in terms of drawing on the relevant literature and is it methodologically, analytically and scientifically sound?
   Yes / No Comments:

   d) Are appropriate debrief details provided?
   Yes / No Comments:

   e) Has the applicant provided appropriate details of where the research will take place?
   Yes / No Comments:

   f) Has the applicant provided appropriate details concerning data analysis?
   Yes / No Comments: Kerry will probably also carry out t-tests – but this can be discussed with supervisor.

4. Ethical Issues (Qu 9)

a) Is there consideration of how to minimise, manage and monitor issues of distress and harm, however minor?
Yes / No Comments:

b) Are appropriate details regarding the use and management of deception provided?
Yes / No / N/A Comments:

c) Has the applicant provided appropriate details including regarding permission and appropriate health and safety information for conducting the study at the proposed location? Is the necessary documentation attached?
Yes / No Comments: online study

d) Has the applicant provided an appropriate overview of how they would manage participant distress?
Yes / No / N/A (online study) Comments:

5. Sample size, participants and recruitment (Qu 10 – 14)

a) Has the applicant provided appropriate details of the sample and how it will be identified?
Yes / No Comments:

b) If using social media for recruitment have details been provided on

a. Proposed sites
Facebook ☐
Twitter ☐
Instagram ☐
Other, please Specify Support groups
Comments:

b. Social media messages?
Facebook ☐
Twitter ☐
Instagram ☐
Other, please Specify Support groups
Comments:

c) Has the applicant provided appropriate details and attached the necessary documentation concerning their recruitment procedures? In particular, have they appropriately considered how to minimise, manage and monitor issues of distress and harm during recruitment?
Yes / No Comments:

d) Are there appropriate details on the information sheet regarding the following (if applicable):

- Purpose of the study Yes / No / N/A
- Explanation of why participant has been chosen Yes / No / N/A
- Details of materials/stimuli/qualitative topics Yes / No / N/A
- Notification that materials used in the study are not diagnostic tools/therapy Yes / No / N/A
- Notification that participation is voluntary Yes / No / N/A
- Incentives/Compensation Yes / No / N/A
- Informed consent Yes / No / N/A
- Procedure Yes / No / N/A
- Time commitment Yes / No / N/A

- Right to not answer questions Yes / No / N/A
- Withdrawal Yes / No / N/A
- How partially collected data will be used Yes / No / N/A
- Benefits and risks of participating Yes / No / N/A
- Anonymity Yes / No / N/A
- Confidentiality Yes / No / N/A
- Dissemination information Yes / No / N/A

6. Dissemination (Qu15)

a) Has the applicant provided appropriate details concerning research dissemination?
Yes / No Comments:

b) Are there appropriate details regarding any specific considerations about sharing the research?
Yes / No Comments:

7. Participant payments and inducements (Qu16)

a) Are there appropriate details regarding compensation arrangements?
Yes / No / N/A Comments:

8. Debrief (Qu17)

a) Are appropriate debrief details provided?
Yes / No / N/A Comments:

b) Are there appropriate details about how participants will be debriefed should they decide to withdraw from an online study?
Yes / No / N/A (not online study) Comments:

9. Data Security (Qu18)

a) Has the applicant provided appropriate details concerning data protection and storage?
Yes / No Comments:

b) Have security issues been properly considered?
Yes / No Comments:

c) Are there appropriate details regarding how privacy and confidentiality will be maintained during dissemination?
Yes / No Comments:

10. Forum-based projects

a) Is the content of the website openly accessible?
Yes / No Comments:

b) Has the applicant discussed what will happen with users who expressly state that they do not wish their responses to be used for research purposes?
Yes / No Comments:

c) Has the applicant explained how online data collected will be anonymized?
Yes / No Comments:

d) Has the applicant explained process of access, should the host website require posts to be posted through moderators

Yes / No Comments:

e) Has the applicant detailed how, where appropriate, they will ensure that age limits are met?
Yes / No Comments:

General comments: Supervisor will discuss with Kerry the use of t-tests and including information on partially used data on the information sheet.

Review status (please highlight one of the following):

Chair's action
Staff/PGR for full review
UG/PGT for full review
Work with external agencies
Work with vulnerable participants
Other issues/concerns

NAME: Linda O'Neill

ROLE: Supervisor / Reviewer 1 / Reviewer 2

DATE: 19/02/18

University of Chester

UNIVERSITY OF CHESTER, DEPARTMENT OF PSYCHOLOGY
APPLICATION FOR ETHICAL APPROVAL AMENDMENT FORM

A) Applicant and personnel

Applicant: *Kerry Keane*
Project title: *Parental well-being: Caring for a child with a disability*
Applicant status: ☐ Staff → Go to Section B ☒PGR ☐Undergraduate ☑Postgraduate taught
Supervisor: *Linda O'Neill*

B) Declaration

1. ☒ I have submitted an application for ethical approval to the Department of Psychology Ethics Committee and I am required to make the following amendments to my application.
   List the recommendations of the committee. *1. "The social media message states that only biological parents should take part, as there is no genetic biological like being looked at, what if IVF was involved or the child is adopted?"*
   2. "Recruitment is to be of fathers/mothers, but one of the questionnaires refers to mothers only in some questions. This may be worth rephrasing."
   3. "Including information on partially used data on the information sheet"
   4. "Using t-tests during analysis"
   Describe how you have addressed these requirements. *1. The messages used to recruit participants, and on all documents relating to the study, will have the word 'biological' removed in regard to parents. All parents will be invited to take part in the study.* (see Appendix 1)
   2. Questions used in the questionnaires have been rephrased to use neutral language, i.e. in questions that refer only to 'mothers', this has been replaced to refer to a 'parent'. (see Appendix 2)
   3. The information sheet has been amended to inform participants that any partially collected data will not be used for analysis and will be disregarded. (see Appendix 3)
   4. Discussed with supervisor and will now add t-tests to the analysis of the data in order to compare differences between groups. (see Appendix 4)

2. ☐ I have submitted an application for ethical approval to the Department of Psychology Ethics Committee that was approved on Click here to enter a date.
   I wish the committee to consider the following amendments I would like to make to the research plan (attach the original approved application form) Click here to enter text.

☐ I am a member of staff. **Signed:** _____ **Date:** 28/02/2018
Print the amendment form on BLUE PAPER and submit to the Dept. Office
☒ I am an UG/PGT/PGR student. I have discussed any amendments with my project supervisor.
Print the amendment form on BLUE PAPER and submit to the Dept. Office

Signed: K. Keane **(Lead Applicant) Date:** 28/02/2018

Supervisor comments:
I have discussed the recommendations of the committee with the applicant and I am satisfied they have met the stated requirements./I support the amendments to the research plan. (delete as appropriate)
☑ Yes Sign and date the form ☐ No Comments: Click here to enter text.

Dapec KKLO/0/0318

Signed: L.P. O'Neill **(Supervisor) Date:** 28/02/18 Click here to enter a date.

COMMITTEE COMMENTS:

☑ ACCEPTABLE: You may now commence with data collection subject to approval from any relevant external agencies.

Interesting study
- good luck.

DATA COLLECTION IS NOT PERMISSABLE UNDER THESE CONDITIONS

☐ ACCEPTABLE SUBJECT TO SUBMISSION OF FURTHER AMENDMENT FORM.

☐ Acceptable subject to conditions listed by chair. Discuss conditions highlighted with supervisor and submit ethics application amendment form direct to office.

☐ Acceptable subject to conditions listed by chair: Submit ethics application amendment form direct to office.

Signed:  Date: Click here to enter a date. 6/3/14

Appendix B1

Appendix B: Facebook Message.

For my Masters Dissertation Project, I am required to complete a piece of work related to a specific field of my choosing. Therefore, I hope to look at the mental wellbeing of parents who have children with disabilities. I also intend to look at the influence of hope and access to services and whether they effect parental mental wellbeing. I would appreciate it if you could take 20 minutes out of your day to complete this short questionnaire. All information collected is anonymous and confidential throughout the completion of the questionnaire and after submission. All parents are asked to take part in this questionnaire, both mothers and fathers who have children that have at least one disability and those with typically developing children. If you would like to take part please send me a message and I will forward you the link to the questionnaire. Thank you.

Appendix 1.

Appendix C: Discussion board Message.

Hello,
My name is Kerry and I am a Family and Child Psychology Masters student. For my Masters Dissertation Project, I am required to complete a piece of work related to a specific field of my choosing. Therefore, I hope to look at the mental wellbeing of parents who have children with disabilities. I also intend to look at the influence of hope and access to services and whether they effect parental mental wellbeing. If you would like to take part could you please respond to the following email address: and you will be informed of how to access the study. All information collected is anonymous and confidential throughout the completion of the questionnaire and after submission. All parents are asked to take part in this questionnaire, both mothers and fathers who have children who have a disability and those with typically developing children. If you would like to take part please send me a message and I will forward you the link to the questionnaire. Thank you.

Appendix 1.

Appendix D: Email

Hello,

My name is Kerry Keane and I am a Family and Child Psychology Masters student at the University of Chester. For my Dissertation Project I am required to complete a piece of work in an area of my choosing. Therefore, I am hoping to look at the mental wellbeing in parents of children with disabilities. I also want to look at the role of hope and access to services and whether this influences mental wellbeing. I would appreciate it if you could take 20 minutes out of your day to complete this short questionnaire. All information collected is anonymous and confidential throughout the completion of the questionnaire and after submission. All parents are asked to take part in this questionnaire, those who have children who have been diagnosed with a disability and those with typically developing children. If you are willing to take part, you can click the link below that will take you to the necessary page. Thank you.

Kind Regards,

Kerry.

Appendix 2

Please rate the extent to which you agree or disagree with each of the following statements.

Strongly Disagree	Somewhat Disagree	Disagree	Agree	Somewhat Agree	Strongly Agree
1	2	3	4	5	6

1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired. 1 2 3 4 5 6
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his / her present age. 1 2 3 4 5 6
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot. 1 2 3 4 5 6
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. 1 2 3 4 5 6
5. My parents were better prepared to be good parents than I am. 1 2 3 4 5 6
6. I would make a fine model for a new parent to follow in order to learn what they would need to know in order to be a good parent. 1 2 3 4 5 6
7. Being a parent is manageable, and any problems are easily solved. 1 2 3 4 5 6
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one. 1 2 3 4 5 6
9. Sometimes I feel like I'm not getting anything done. 1 2 3 4 5
10. I meet by own personal expectations for expertise in caring for my child. 1 2 3 4 5 6
11. If anyone can find the answer to what is troubling my child, I am the one. 1 2 3 4 5 6
12. My talents and interests are in other areas, not being a parent. 1 2 3 4 5 6
13. Considering how long I've been a parent, I feel thoroughly familiar with this role. 1 2 3 4 5 6
14. If being the parent of a child were only more interesting, I would be motivated to do a better job as a parent. 1 2 3 4 5 6
15. I honestly believe that I have all the skills necessary to be a good parent to my child. 1 2 3 4 5 6
16. Being a parent makes me tense and anxious. 1 2 3 4 5 6
17. Being a good parent is a reward in itself. 1 2 3 4 5 6

Appendix 3.

Appendix E: Information Sheet.

You are being invited to take part in a study that aims to look at the mental wellbeing of parents who have children with disabilities. In addition to this, the study will also look at the mediating role of hope and access to services on mental wellbeing. Anyone who is a parent is invited to take part; those who have children with a disability and those with typically developing children, as I am hoping to compare the mental wellbeing of parents with typically developing children against that of parents with children who have a disability. You may also enjoy learning about any results that are concluded from the study.

Please carefully read through the following information sheet before you decide whether you would like to take part in the study.

This study is made up of an online questionnaire that will take around twenty minutes to complete. It contains questions that will relate to stress levels, levels of hope, perceived parental competence and social support. For your own anonymity you are asked to ensure that you refrain from using any identifying information. The questions used are for research purposes only and should not be used in any way as a diagnostic tool. It is important that you answer all of the questions that are listed, though if you feel that you cannot continue you are able to withdraw from the study at any time by exiting the screen, though please be advised to keep clicking the 'next' button at the bottom of the page so that you can access the debrief sheet with helpline numbers if required. Any partially collected data will not be used in the study and will be disregarded. Once you have submitted your completed questionnaire you will no longer be able to withdraw your information as it will all be completely anonymous and therefore will not be able to be located.

Please note that answers are not marked as correct or incorrect, you are only asked to answer these questions as honestly as possible as they relate to you. Once you have completed the study, you will be directed to debriefing form which will include additional helpline numbers that you are able to contact if you feel that any part of the study caused you any distress.

All of the information that is collected will be completely anonymous and will remain confidential at all stages of research. I would like to reiterate that participation is voluntary; it is solely your decision to take part in this study.

It is important to note that completion of the questionnaire signifies that you have given your consent to take part and allow your data to be analysed.

I would like to thank you for reading this information sheet and taking part in this study. All contact details, for any additional information you would like to know, can be found below.

Researcher: Kerry Keane- 1304170@chester.ac.uk
Supervisor: Dr Linda O'Neill- Loneill@chester.ac.uk Telephone: 01244 513193
Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Thank you for your time and for reading this information sheet.
Kerry Keane.

Appendix 4

(Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989) and The Adult Dispositional Hope Scale [AHS] (Snyder et al, 1991) and the Multidimensional Scale of Perceived Social Support [MSPSS] (Zimet, 1988).

In particular the PSS was chosen as a method to assess parental stress, as it has consistently reported high levels of validity and reliability across populations (Wu & Amtmann, 2013). The PSOS will be utilised as it has shown great generalisability across samples and has been used not only in research focusing on maternal sense of competence (Karp, Lutenbacher & Wallston, 2015) but also to study paternal sense of competence (Chan, Leung & Johnston, 2000); something that will benefit the current research. The PSOS measures perceived competence of parents on two dimensions: satisfaction and efficacy (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989).

The AHS will be included within this study and participants will be asked to relate these questions to parenting a child with disabilities, as previous research has tended to focus on the negative issues that can arise when caring for a child with a disability, including illness, pressure and maladjustment (Kandel & Merrick, 2007). Therefore, the current study would like to build upon this and highlight the possibility of positive functioning that may also occur when caring for a child with a disability.

Finally, the MSPSS will be used to assess the relationship between perceptions of social support and wellbeing. The MSPSS is a 12-item scale that usually assesses relationships with family, friends and a significant other. As an assessment tool, this scale has been shown to be a solid research instrument (Stewart, Umar, Tomenson & Creed, 2014; Zimet, Dahlem, Zimet & Farley, 1988). For the purpose of this study, this scale will still address three subscales of support, though these will instead be 'family', 'significant other' and 'access to services'. So, though two subscales will remain the same, questions relating to 'access to services' will replace the questions relating to 'friends' in this scale (see appendix A), as this is the factor my study aims to focus on.

Additionally, access to services as opposed to support from friends has been reported by parents who have a child with disabilities, as a more beneficial resource to them (Beresford, Rabiee & Sloper, 2007). This will be a simple change, for instance one of the typical MSPSS questions relating to 'friends' reads "I have friends with whom I can share my joys and sorrows". The revised question here will actually read "I can easily access a support service that I am able to share my feelings with". Thus, the question overall will be examining similar feelings though it will be worded differently to investigate an alternative subscale.

This study will be a between-subjects design. The results will first be analysed using descriptive statistics and further analyses will include t-tests, correlation analysis, hierarchical multiple regression and mediation analysis using PROCESS (Hayes, 2013).

7b. Provide details of your contingency plan

Notes: Please briefly describe your contingency plan. (100 words)

A contingency plan has been discussed with supervisor. For instance, as supervisor has much experience in this area, we have discussed the possibility of investigating sibling wellbeing, in place of parental wellbeing, if it is not possible to get enough participants for the original idea to investigate the wellbeing of parents who have children with disabilities. Supervisor has sufficient existing data available for this.

8. Provide details of the previous experience of the procedures by the person conducting the study.

Notes: Say who will be undertaking the procedures involved and what training and/or experience they have. If supervision is necessary, indicate who will provide it.

Supervisor has much experience in this area and in statistical analysis, and researcher also has experience in statistical analysis.

Appendix B: Adapted multidimensional scale of perceived social support (MSPSS). (Questions that were changed from assessing "friend" support to "access to services" support are in bold).

	Very strongly disagree						Very strongly agree
1. There is a special person that is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really try to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. I feel I receive sufficient and frequent help from the support services that are available to me.	1	2	3	4	5	6	7
7. I can count on support services to provide helpful information and resources when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I can easily access a support service that I am able to share my feelings with.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. There is always a support service accessible to me where I can talk about my problems if I need to.	1	2	3	4	5	6	7

Appendix C: Participant Information Sheet.

Page 1: Important Information

You are being invited to take part in a study that aims to look at the mental wellbeing of parents who have children with disabilities. In addition to this, the study will also look at the mediating role of hope and access to services on mental wellbeing. Anyone who is a parent is invited to take part; those who have children with a disability and those with typically developing children, as I am hoping to compare the mental wellbeing of parents with typically developing children against that of parents with children who have a disability. You may also enjoy learning about any results that are concluded from the study.

Please carefully read through the following information sheet before you decide whether you would like to take part in the study.

This study is made up of an online questionnaire that will take around twenty minutes to complete. It contains questions that will relate to stress levels, levels of hope, perceived parental competence and social support. For your own anonymity you are asked to ensure that you refrain from using any identifying information. The questions used are for research purposes only and should not be used in any way as a diagnostic tool. It is important that you answer all of the questions that are listed, though if you feel that you cannot continue you are able to withdraw from the study at any time by exiting the screen, though please be advised to keep clicking the 'next' button at the bottom of the page so that you can access the debrief sheet with helpline numbers if required. Any partially collected data will not be used in this study and will be disregarded. Once you have submitted your completed questionnaire you will no longer be able to withdraw your information as it will all be completely anonymous and therefore will not be able to be located.

Please note that answers are not marked as correct or incorrect, you are only asked to answer these questions as honestly as possible as they relate to you. Once you have completed the study, you will be directed to debriefing form which will include additional helpline numbers that you are able to contact if you feel that any part of the study caused you any distress.

All of the information that is collected will be completely anonymous and will remain confidential at all stages of research. I would like to reiterate that participation is voluntary; it is solely your decision to take part in this study.

It is important to note that completion of the questionnaire signifies that you have given your consent to take part and allow your data to be analysed.

I would like to thank you for reading this information sheet and taking part in this study. All contact details, for any additional information you would like to know, can be found below.

Researcher: Kerry Keane- 1304170@chester.ac.uk Supervisor: Dr Linda O'Neill- l.oneill@chester.ac.uk Telephone: 01244 513193

Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Thank you for your time and for reading this information sheet.

Kerry Keane.

Appendix D: Participant Debrief Sheet.

Debriefing

Your responses to this survey have been submitted.

If you need a formal record of your submission, please use the following details:

Completion receipt

Receipt number: 1-1-1
Submission time: 2018-09-19 10:58:58 BST

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I would like to thank you for completing this questionnaire and taking part in the research being conducted. Again, I would like to reiterate that the questions used within this questionnaire are used for research purposes only and should not in any way be used as a diagnostic tool. Any information that is collected will be kept confidential and the concluding data will be published anonymously.

If you are interested about the topic, or would like to know more about the research results, you are welcome to email any queries to the contact details that are listed below.

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The main purpose of this study is to understand whether parenting a child with disabilities has a negative impact on parental mental wellbeing. This investigation also intends to look at the influence of hope and support, and whether these variables moderate the results.

There has been previous research conducted in this area that has provided guidance for the research hypothesis for the current study, those being:

- There will be decreased psychological wellbeing in parents of children with a disability than the control group.
- There will be increased levels of psychological wellbeing in parents who have frequent access to support than those who have more limited support.
- We are also trying to establish whether there is a difference in hope levels in parents who have children with disabilities and the control group.

If you feel that your participation in this research study has caused you any distress or harm, you are advised to speak to someone as soon as possible. There are helpline numbers provided below that you are able to contact:

The Parents Helpline: 0808 802 5544

Family Lives: 0808 800 2222

Contact a Family: www.cafamily.org.uk – Helpline number: 0808 808 3555

Disabled Parents Network: www.disabledparentsnetwork.org.uk – Helpline number: 0870 241 0450

Samaritans: jo@samaritans.org - Helpline number: 116 123 (UK).